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Proceedings are presented from a 1980 conference on community based services for families of developmentaly disabled children. The following ten papers are included: "Leading Edge Services to Families of Persons with Developmental Disabilities" (R. Perske); "Family Resource Services and Support Systems for Families with Handicapped Children" (B. Loop, W. Hitzing); "Supporting the Handicapped and Their Families in Rural Areas" (A. Hofmeister); "Manual of the Parent Respite Care Cooperative" (The Co-op Committee of Kalamazoo Association for Retarded Citizens); "Respite Care--A "How-to" Manual" (G. Carron); "Mental Health Services for Families of Developmentally Disabled People" (R. Rubin); "The Needs of Developmentally Disabled Persons and Their Families" (P. Smith, J. McGee); "Nebraska Legislative Issues" (J. McGee); "Nebraska's Role in Supporting the Family" (J. McGee); and "Constitutional Issues for Families in Nebraska" (B. Mason, A. Mason). (CL)

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FAMILY RESOURCE SYSTEMS:

THE NEBRASKA MODEL

January 24 - 25, 1980

Sponsored by:

The Nebraska Governor's Planning
Council on Developmental Disabilities
&
Meyer Children's Rehabilitation
Institute - Family Rehabilitation Program

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PREFACE

Historically, the development of community based services has not focused on alternatives that have emphasized family resources. More recently, some communities have initiated services to support families with developmentally disabled persons.

The Family Resource Systems Conference was designed to present models and programs that are individualized and responsive to the needs and concerns of consumers and their families. The major sessions, panels, and group workshops brought together leaders from around the country. The end product of this conference contained in this publication is the components of a community model of family resource services for Nebraska that are integrated into the mainstream of the community.

The evaluation reports on the conference demonstrated that it was highly successful. The planning committee would like to thank all of the speakers who took time away from their busy schedule to speak at the conference. We would also like to thank the Governor's Council for financially supporting the Conference and M.C.R.I. for the staff support that made the Conference so profitable. But most of all, we would like to thank the many parents who planned, attended, participated and helped make the Conference such a success.

The idea for the Conference came from Beth Macy, State Developmental Disabilities Director and was ably carried out by staffer Eric Evans. The real credit for the success of the Conference however, belongs to Patty Smith, John McGee, and Bertine Loop.

These three individuals helped to organize, plan, acquire speakers, and generally worked extremely hard. Your contributions to the Developmentally Disabled and their Families will not soon be forgotten.

In addition, Lang Anderson's contribution in the graphics and compilation is also appreciated.

In summary, we hope that this Conference will be the beginning of a new era of providing resources to families with the developmentally disabled individuals.

Jack A. Stark, Ph.D.
Editor

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CHAPTER 1

FAMILY RESOURCE SYSTEMS CONFERENCE

Speech by Ruth R. Thone

Omaha-Thursday, January 24, 1980

I am very honored and privileged to be here with you this morning and to open Nebraska's Conference on Family Resource Systems. We will be talking about the Nebraska Model Support Systems for families of handicapped persons.

This conference symbolizes what Nebraskans, among others, have long held to be precious and fundamental. The family is the central focus of our life. As families with disabled members come together to support one another so do the professionals in this area of human concern. Our audience this morning is made up both of people working professionally in the field and families looking for help and sharing with one another.

Strangely enough, pain causes us to give of our best to one another, after we've come through the initially startling experience of not being able to control this life or get what we thought we wanted from it.

It's too bad that we all aren't as grateful for our life as I'm sure you people are, working as closely as you do with those who struggle much harder to live.

As I thought of talking to you this morning I was reminded of Jean Vanier, the person whose love and vision has made possible homes at L'Arche in France and in Canada for the disabled. Vanier's mission is one of acceptance in action. His love does not need to make people productive as a sign of their worth at L'Arche the week and the strong are equally valued.

In many cases the community becomes the family, this is the International Year of the Family, and I must say that I sometimes think very little of International Year of the Family. Some of them, I think, are

make work and God knows we don't need any made up work in this life, but the Year of the Family feels right and is very significant. I have some familiarity with ancient Chinese wisdom through the use of the ICHING and over and over and over again the Chinese refer back to the family as a source of our strength. They say look at what's going on in the family and you will see what is going on in the world and solve what is going on in the world by solving what is going on in the family.

We are beginning to know again that that seeking for community which many of our young people in this country were doing in the sixties means to come home again, means to come home to the family whether of origin or design. We are that family to one another.

Especially you people, it seems to me, become family, become an extension of the nuclear family to the families with disabled members. Perhaps you helping professionals become a new model of the generational family concept.

We must make sure that what we do both with public and private monies and energy supports family life in Nebraska, brings programs as close to the community level as possible and involves families in the process.

Families with disabled children present a challenge to this commitment. Most families can integrate their disabled child into the family with little or no extra effort. The strength of the family system is tested, however, when confronted with the child having a severe, chronic disability especially when there is no readily available support system involving rapid diagnosis, early intervention and the knowledge there will be the services necessary to meet the needs of the child and the family throughout the child's life.

Our State has long been a leader in the development of such services; helping one another is something we turn to easily here. Perhaps since we are freed from the stresses of mere survival that people in larger metropolitan areas and other parts of the world live under, are we better able to be concerned with helping one another.

The days are long gone when families have nowhere to turn. Our early intervention and preschool law for handicapped children insures appropriate services for the child with developmental needs from birth if necessary. These services are provided through local school districts where families reside, we are therefore moving toward the earliest intervention possible. Improvement will occur in early diagnosis and intervention as the public and the professionals become more aware of this option that is so supportive of family life.

Likewise, through the Nebraska Department of Education and local school districts our school age handicapped children have the right to a free public education in the least restrictive setting, close to home and within their community. The past few years have witnessed fast progress toward this fundamental right to an education.

There are still individual problems with both the preschool and school age program. However, the very fact that today we have only ten children below the age of six in our state institutions clearly demonstrates the State's desire to keep children with disabilities at home and in their communities if this is where they can best be helped.

I am very aware that this is a most controversial subject in our State today and I simply want to say to you that we are committed not only

to the healing process of family and community setting but to providing the best possible environment for those who must remain within an institution.

Older handicapped citizens have also been the focus of legislative and program change in recent years. More and more handicapped children are living with their families and more and more are returning to their families from state institutions.

The theme of this conference is to look closely at the needs of families with disabled children in the context of state and local programs and laws so that we can develop an agenda for the eighties. There is a number of improvements that can be made over the next decade. An often needed but seldom available service for these families is respite care. Any survey of families with handicapped children asking for the most urgently needed service would almost unanimously conclude that respite services to the family would provide the greatest benefit toward maintaining the family intact and healthy. Families often want to maintain the disabled child in the family setting. The systematic and readily available provision of respite care would help most families keep their child at home with relative ease for longer periods of time.

Another possible improvement which we should consider is the development of volunteer parent support groups across the state.

I want to tell you that I am somewhat involved in an organization called "Parents Anonymous", with which most of you are familiar. It was organized to attack the monster of child abuse by supporting, sharing and strengthening parents and parenting. Some of the best family support comes

from one parent helping another. Such pilot parent programs would further help, especially young families with a newly born disabled child.

You are aware, of course, of legislative proposals to subsidize "at risk" families so that these families would receive a small subsidy from the state in order to buy such services as respite care. This kind of approach would bring the decision making direction to the family.

There are a number of new approaches to examine in this conference so that over the next few years families with disabled children will be strengthened rather than supplanted by the Government.

All programs public or private must support not supplant family life. We literally cannot take over family function. We can try but it is doomed to failure. Family strength comes from a functioning compassionate unit, whether of origin or design. The public - you and me - do not create it. We can only help.

Always praying and working to insure that our dependence on one another become interdependent-each of us knowing why we are here and sharing that gift.

CHAPTER 2

Robert Perske
159 Hollow Tree Ridge Road
Darien, CT 06820
203-655-4135

Leading Edge Services to Families of Persons
With Developmental Disabilities

This is a highlighting of workable family support systems which are featured in the Report to the President entitled:

Mental Retardation: The Leading Edge--Service Programs that Work.

The Report can now be obtained for free by writing to:

The President's Committee on Mental Retardation
Washington, DC 20201

The idea for this report came from Mrs. Rosalynn Carter when in a meeting with the committee she requested that they provide her with information on "programs that are working well." Shortly after this request, a timelined sequence of tasks was planned and carried out. The plan included:

- Utilizing information on a previous Random House/HEW search for workable programs for persons with severely and profoundly handicapping conditions. The data covered 600 program efforts.

- Taped telephone visits with:

  20 PCMR Members who are situated in different geographical areas of the nation.
  8 PCMR Consultants.
  5 PCMR Staff Members.
  50 knowledgeable professionals and volunteers in the field who are situated in different geographical areas.

- Taped conversations with 225 program services, utilizing a checklist of topics which were covered.

- On-site interviews of persons with handicaps and their parents. Then, when it was clear that persons with the handicaps had indeed achieved measureable growth or an increased quality of living, the programs producing such gains were visited. Consequently, taped interviews and observations of programs in action took place at 70 different locations across the nation.

- Out of the 70, twenty-nine programs were chosen for the report. In no case were the selected programs seen as being "the top" of the "number one" available services. Instead, each one described a specific sequence of actions that could be considered for replication elsewhere.

- FORTY-FIVE WELL-TRAINED PARENTS OF CHILDREN WITH DD COME TO THE AID OF PARENTS WITH SIMILAR PROBLEMS WITHIN 24 HOUR REQUEST FOR HELP. (This sophisticated agency channels the latest technologies and attitudes into effective peer-group contacts.)

  Pilot Parents, Omaha, NE.

- SOME PARENTS UNDERGO INTENSIVE TRAINING. . . BECOME OFFICIAL PROGRAM COORDINATORS OF THEIR OWN CHILD.

  Parents As Professional Program Coordinators, Orange County, CA.

- A NETWORK OF 24 FAMILY ADVOCACY OFFICES UNSNARL BUREAUCRATIC RED TAPE ON BEHALF OF FAMILIES HAVING CHILDREN WITH HANDICAPS.

  The Troubleshooters of Washington State, Seattle, WA.

- ANY CHILD FROM BIRTH TO FIVE YEARS, WHO IS HANDICAPPED OR "AT RISK" BECOMES A PUBLIC SCHOOL STUDENT IMMEDIATELY.

  Spring Harbor Elementary School, Madison, WI.

- A SMALL TOWN PUBLIC SCHOOL HELD THEIR OWN CHILDFIND. . . INTEGRATED SEVEN STUDENTS WITH SEVERE-PROFOUND HANDICAPS.

  Molly Stark Elementary School, Bennington, VT.

- THIRTY-TWO STUDENTS TRANSFER FROM A SPECIAL SCHOOL TO A REGULAR SCHOOL. . . TODAY ALL STUDENTS WITH DD ARE IN REGULAR SCHOOLS THROUGHOUT THE CITY. (Parent involvement was a key to the success.)

  Badger and Glendale Schools, Madison, WI.

- AN ALERT FAMILY WITH A GIFTED SON AND A RETARDED SON (TWINS) USE DETAILED DOCUMENTATION TO MAINSTREAM A PUBLIC SCHOOL.

  Owen J. Roberts Middle School, Pottstown, PA.

- A GRASSROOTS ATTEMPT TO PROVIDE RESIDENCES FOR ALL OF ITS CITIZENS WITH DD. . .UTILIZING DECENTRALIZED CLUSTER SYSTEM. . .ALL BUILT ON THE FOUNDATION OF SUPPORT-THE-FAMILY FIRST.

  Eastern Nebraska Community Office of Retardation, Omaha, NE.

- AN INSTITUTION MAKES A TURNABOUT AND BECOMES A COMMUNITY-BASED SERVICE. (Family involvement is seen as a key force.)

  Macomb-Oakland Regional Center, Mt. Clemens, MI.

- THIS UNIQUE AGENCY SERVES PERSONS WITH BOTH MENTAL ILLNESS AND DEVELOPMENTAL DISABILITIES WHO HERETOFORE WOULD HAVE FALLEN INTO THE GAP CAUSED BY THE MH/MR SPLIT.

  Rock Creek Foundation for Mental Health, Bethesda, MD.

Suggestions for reading the report. When you get your own copy, read first the summary on page 73 and 74. These concepts, attitudes and beliefs were distilled from the highlighted programs. Then, read the brief introductions to the 29 programs. By doing this, one can sense the overall direction the report has taken. Finally, the reader is encouraged to skip around and choose the program services that grab his or her interest first.

The family support services. For two and a half hours, I discussed in detail selected services from the report. Most of what was spoken came from the Report. Therefore, the services are only listed here along with "headline" descriptions of programs which were presented in the Report.

- ALL "AT RISK FOR DD" NEWBORNS LEAVING HOSPITAL INTENSIVE CARE UNITS RECEIVE FOLLOW-UP CARE FOR ONE YEAR. (All existing agencies join forces and deliver the services.)

  FIND (Follow-up Intervention for Normal Development), San Bernardino, CA.

- A TRAVELING TEACHER MAKES IN-HOME EDUCATORS OUT OF PARENTS WITH NEWBORN CHILDREN WITH DOWN'S SYNDROME. (After three years the children function close to the normal milestones.)

  Down's Syndrome Infant-Parent Program, Eugene, OR.

- THIS STATE PROVIDES DIRECT IN-HOME SERVICES--ESPECIALLY RESPITE CARE. (The State Bureau of Developmental Disabilities, University of Washington, Red Cross and organized consumer advocates have made it happen.)

  The Home-Aid Resources of Washington State, Olympia, WA.

- ONE OF 20 COMMUNITY-BASED SERVICE UNITS ADDRESSING SPECIFIC NEEDS IN ETHNIC NEIGHBORHOODS. (The product of a dispersed staff of a large institution that was never built.)

  The South Bronx Community Services Team, The Bronx, NY

- AN AVANT GARDE FAMILY WITH A CHILD HAVING SEVERE AND PROFOUND HANDICAPS HAS MADE ITS HOME A TRAINING RESIDENCE FOR FIVE MORE CHILDREN WITH S-P HANDICAPS. (Both the children and parents are trained.

  The Somerset Home School, Charmichael, CA.

. PARENTS TRAIN PARENTS TO HELP THEIR CHILDREN WITH BEHAVIORAL DISORDERS.

Regional Intervention Program, Nashville, TN.

Well-run programs for families with persons having handicaps--like those mentioned above--have led us to a single startling conclusion:

> We are at a turning point in the way our nation treats such families: Up to this point, families in our nation received more incentives for sending their children with handicaps out of the home. Now, enlightened governments, volunteer organizations, neighborhoods and ordinary citizens--for the first time in history--are providing more incentives for keeping children with their families.

"Until a few years ago," a medical doctor in California stated, "We were utterly 'brilliant' in splitting up such children from their moms and dads. Now, we have come to see how really stupid we were for doing that. We are beginning to stop it. . .We find it is so much wiser to do everything we can to support that family and to keep that family together." Thirty years ago, such a statement from a physician would have been almost unthinkable. But now that we have reached this crucial turning point, more and more professionals, volunteers and ordinary citizens will accept such support-the-home-first efforts as common practice. Here's hoping the presentation of these family support services will strengthen and reinforce this new incentive.

FAMILY SUPPORT

SOME ADDITONAL ARTICLES AND BOOKS:

"The Extend-A-Family Program" in Listen Please. A free copy can be obtained by writing to Canadian Association for the Mentally Retarded, Kinsmen NIMR Bldg., York University, 4700 Keele St. Downsview, Ontario, Canada M3J 1P3.

"The Pilot Parents of Montreal" in Listen Please. The same free issue that's listed above.

Perske, Robert. New Directions for Parents of Persons Who are Retarded. Abingdon Press, Nashville, TN 37202. Price $1.95.

Porter, Fran. A Design for Developing a Program for Parents of Handicapped Children. (Edited by Robert Coleman) Greater Omaha Association for Retarded Citizens, 3212 Dodge Street, Omaha, Nebraska 68131. Price: $10.50.

CHAPTER 3

FAMILY RESOURCE SERVICES
AND
SUPPORT SYSTEMS
FOR
FAMILIES WITH HANDICAPPED CHILDREN

Bertine Loop with Wade Hitzing

". . . One of the most basic of all rights is that of children having the right to live with their own families. The importance of living with your own family is well documented. . . and protected by laws and courts throughout the nation.

The protection of this right so well afforded to 'normal children' has not been equally applied . . . Indeed, while Department of Social Service and/or Public Welfare Departments have instituted plans to assist family members in coping with personal life problems and the maintenance of the family unit, professionals in the field of Developmental Disabilities have offered out-of-home alternatives to developmentally disabled family members as the key to maintenance. The apparent rationale for this is the belief that the natural family is seldom if ever capable of providing a habilitative environment and program for their developmentally disable child and/or that without removal of the child, the family will undergo disintegration.

An underlying assumption of the Community Placement Plan is that wherever possible and appropriate the placement site of <u>choice</u> is in the natural family. Likewise, when support services are required for developmentally disabled persons and/or their families, the intention for provision of these services is that of maintaining and individual in his or her own natural home."

<u>Willowbrook Community Placement Plan (1976)</u>

1. Introduction

Services for children with handicaps have undergone considerable development and expansion within the past ten years.

Generally these developments have focused on programs and services in residential settings, schools and other facilities outside of the family system.

Services that focus on developing resources and supports based on the fundamental role of the family as the core of the delivery system for handicapped children have not recieved the same priority status or emphasis.

There are many factors that have influenced these developments. This chapter will discuss those factors and describe: the background and trends in family resource services for handicapped children; a model array of family-centered resources and supports; the current status of consumer involvement and temporary systems of family supports; a model for training families to be self-advocates; and national policy recommendations and strategies for change.

2.1 Overview: Historical Perspective of Services for all Families with Children

Families are the most individual and basic component of the community ecological system. Current bureaucratic approaches to developing services have failed to recognize this important characteristic of the family. Despite important evidence and description of the family as an ecological system by Hobbs, the expansion of social institutions has substituted outside services for those formerly provided within the family system. This has resulted in the systematic removal of families' ability to control services they receive.

Previous to the development of social institution models, the family had been viewed as the major system to provide itself with opportunities, access and services (i.e., "resources"). With the increasing overlays of complex and often confusing organizations, and public bureaucracies have displaced many functions of the family. The family system has become increasingly dependent on formal resource structures, such as schools. labor unions, corporations, units of governments and human services agencies. (see Table I, next page).

Another effect of this formal resources network has been the investment of planning and fiscal priorities in inflexible organizational models.

TABLE I. FAMILY RESOURCE SYSTEMS

LEVEL/TYPE OF FAMILY RESOURCE SYSTEM	EXAMPLES/RESOURCES OFFERED	POTENTIAL DRAWBACKS AND SHORTCOMINGS
NATURAL -nuclear family -extended family	-emotional support, affection -advice, information -counseling, parenting -babysitting, convalescent care -tutoring, instruction -resources location -community manipulation and influence -recreation	1) absence of family supports, helping mechanisms 2) reluctance to use family resources 3) inability of family to meet needs, obtain goals, etc. 4) communication and decision-making barriers 5) value conflicts
INFORMAL -friends -neighbors -co-workers, colleagues -bartenders, hairdressers	-emotional support, affection -advice, information -counseling, parenting -babysitting convalescent care -tutoring, instruction -resources location -community manipulation and influence -recreation	1) absence of access to or rapport with available informal resource person(s) 2) reluctance to use informal resource person(s) 3) inability of informal resource person(s) 4) value conflicts to meet needs, assist in goal attainment, maintain growth, etc. 5) communication and decision barriers
FORMAL RESOURCE SYSTEMS -labor unions -consumer organizations -advocacy groups -professional organizations -self-help	-negotiation, lobbying -recreation -individual and group emotional support, mutuality -advice, information -service system influencing -monitoring, direction	1) non-existence of formal groups 2) reluctance to invest in membership of formal group 3) lack of awareness that specific formal groups resources exist 4) absence or inadequate power, influence and ability of such groups to meet members needs, goals, etc. 5) inadequate procedures, communications, decision-making mechanisms
SOCIETAL RESOURCE SYSTEMS -libraries, schools -hospitals, institutions -voluntary service agencies -legal services -places of employment -social security programs -human service systems	-regulations/policies -medical/health care -brokerage/community resources -monolithic service systems -foster care, respite assistance -public defenders, para professionals, ombudspersons	1) non-existent or inadequate services level 2) geographical, psychological or cultural barriers and restricto access 3) lack of awareness or how to use system 4) existence and operation of system creates new problems or aggravates old ones 5) use of more than one resource systems may result in cross-purposes, trapping family in conflicting demands and contradictory messages 6) internal organization barriers to effectiveness.

In the broad area of services for children, traditional community agencies serving children have not included priority planning for handicapped children. Although the "New Federalism" policies of the 1960's supposedly designed new and expanded services for children, the resulting service "system" outcome was characterized by fragmentation, competition and duplication from the federal level to the local delivery of services. This situation continues today despite current federal policy goals that stress intergovernmental cooperation, accountability and cost-efficiency (Comptroller General of the United States, 1977).

Each major federal program has specialized concerns, coveted models and elitist technology. This territoriality and bureau isolation makes it difficult, if not impossible, to translate policy rhetoric into services based on the basic right of families to be the core component and ultimate controllers of their future community.

Today all parents are, in reality, forced into new roles as advocates, mediators and brokers. Our current human service systems and social institution have not, in fact, developed community resource networks that support the integrity and natural environment of the family.

Current funding restrictions in all areas of human services programs will probably continue and have life-long negative effects on handicapped children and their families.

Critical national reports from responsible groups concerned with the welfare of all the children in the United States have repeatedly identified major factors in national public policy that cause this isolation and lifelong dependency of thousands of families with handicapped children.

2.2. Overview: Historical Perspective of Development of Integrated Community Services for Handicapped Children and Relationship to Policies for All Families.

The development of community alternatives to institutionalization for handicapped children has been a major thrust of the deinstitutionalization movement in the community setting. In terms of regulatory interpretation and funding, however, community alternatives receive less than 10% of the funds available for deinstitutionlization (GAO, 1977, 1979). Further, within the community alternatives the majority of community residential services establisted have been for adults rather than children (Morrell, 1979).

Prevention of institutionalization through services that focus on supporting the family in the natural home environment have finished last when compared to the other thrusts of deinstitutionalization. Financial supports for home-based services, for example, currently receive less than 1% of the total federal expenditures in the area of health and social services.

Recently, community programs and planners are increasingly aware of the limitations to the current approaches for developing services for handicapped children. Agencies discovered that the financial investment necessary for maintaining a handicapped child in a residential program created a disproportionate drain on agency budgets. Further, studies and reports consistently documented the negative effects on family relationships caused by focusing on services offered outside of the family system.

Further, the limited family support services that have been developed have already demonstrated that the costs of community services can be considerably reduced (Gary W. and the United States v. Stewart, United States Department of Justice, 1975).

Further, the limited family support services that have been developed have already demonstrated that the costs of community services can be considerably reduced (Gary W. and the United States v. Stewart, United States Department of Justice, 1975).

P.L.94-142 placed responsibility for the education of handicapped children with local school districts. In many locations this meant that children who had been previously institutionalized could return home and other children were not forced to leave home to obtain an education.

Across the United States, parents of handicapped children have become organized and actively involved in developing resources and services for their families. Usually, the identify family resources and supports as the top program priority as opposed to the low financial priority of planners and legislators.

At the same time systematic application of the principles of normalization and developmental model have been a major influence in the broad acceptance of community-based programs (in places where they are adequately funded and supported).

Nevertheless, in terms of total services, family resource services for handicapped children have still not received the same attention.

Family-centered services have lagged seriously behind educational and residential programs for all children in the United States. Despite professional rhetoric and policies, meaningful family-centered resources and services have been compromised and diffused to fit institutional structures that are, by design and service approach, opposed to the very premise that the home environments of families are the preferred setting for children to grow and thrive in.

Schneiderman (1979) identified several major factors that contribute to this paradox between policy and practice. These factors include:

1) conflicting and confusing definitions of the "family";
2) individual vs. group value orientation and attitudes toward social responsibility;
3) historic public policy attitude of substituting care from alternative social institutions rather than supporting family resource systems;
4) viewing the family as responsible and liable for problems and changes rather than restructuring the service system.

In the past, the failures of service systems to develop resources and supports for families had little to do with the families' needs and abilities. Too often, agencies have presumed to know the resources and needs of families. Lack of involvement by the families was interpreted to mean lack of interest or motivation. Time limitations have often resulted in impersonal letters and notices. Even when agencies remembered to involve the consumers, there was minimal preparation, and little resource information given to consumers that could help them to make decisions and gain access to the decision making. As a result, the service systems were unable to develop and deliver flexible and individualized services that were accountable to the consumers.

The effects of these factors and the resultant conflict of policy and practices has resulted in a linear or continuum approach to services for handicapped children rather than an array of family-centered services that are truly consumer-oriented. In the next section, these two approaches will be discussed and contrasted.

3.1. The Continuum V. the Array Approach to Development of a Community Model of Family-Centered Resource and Support Systems

A. Continuum of Community Environments

During recent years, there has been a growing strategy to develop specific types of community programs for handicapped children and their families. These services are usually educational and/or residential alternatives, with very few programs emphasizing in-home services (early intervention and limited parent training projects are major exceptions).

Community residential programs were developed to provide alternatives to large segregated state institutions. Gradually, there has been a movement towards utilization of smaller nursing homes and large group home facilities. This is substituting one form of institution for another. The continued abusive conditions in nursing homes and institutions have not prevented a major proportion of states from utilizing these alternatives, despite the overwhelming evidence for the support of natural home environments (GAO, 1979).

Community residential programs were originally intended to prepare handicapped children for return to these natural homes (or similar natural environments.). However, both families and professionals often came to view out-of-home community residential programs as permanent.

Because of this lack of movement through the community residential system, many service providers and planners focused primarily on expanding out-of-home residential settings along a continuum (Skarnulis, 1976).

Out-of-home residential services, especially for children, are clearly more restrictive and less normalizing than developing the resources and supports a family identifies as needed to prevent such fractures of the family system.

This type of continuum approach has resulted in a rigid relationship between policy and program development that is also used to develop educational services for handicapped children.

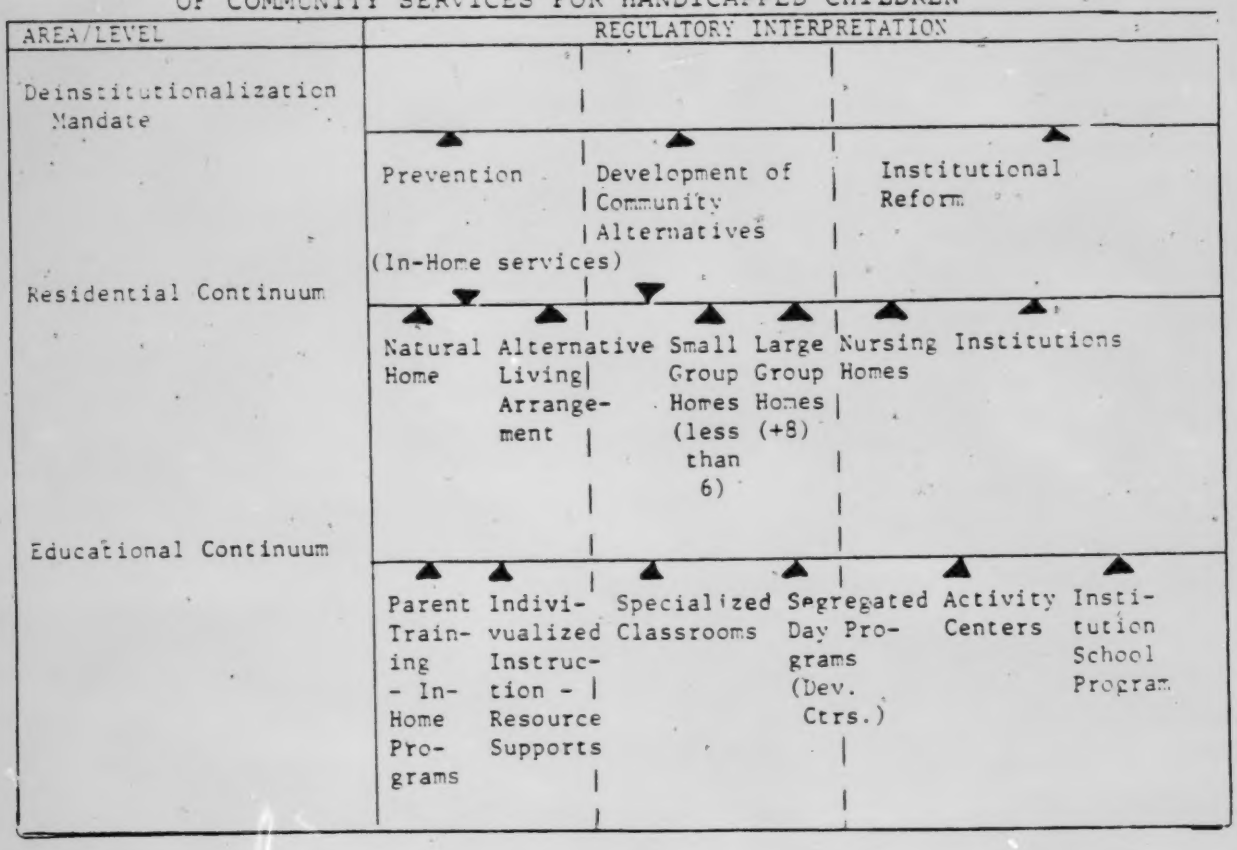
In 1975, civil liberties litigation regarding the right of handicapped children to free, appropriate public education resulted in broad policy reform and legislation (P.L. 94-142).

Public Law 94-142, has regulatory mechanisms to protect and ensure the rights of children primarily through individualized planning ("IEP's") developed by a team that should include the child and parents as equal members. Local and state education programs implementing the mandate of P.L. 94-142 have often not viewed the handicapped child and his/her parents as consumers with specific legal rights (Yaeger, 1979).

The process of negotiating individual education plans was "supposed" to be based on objective analysis of a child's resources as well as his or her needs. The IEP process is currently controlled by educational systems instead of through a shared joint responsibility with families. As a result, the IEP process supports an education system that continues to fit the consumers into a continuum. Handicapped children themselves continue to be categorized by different facility settings and diagnostic labels (Hobbs, 1976).

This continuum approach to developing both residential and educational systems in communities has paralleled the funding priorities of deinstitutionalization. Although these relationships are sometimes contradictory and complex, the current continuum approach to the community development of services for handicapped children can be illustrated as follows:

RELATIONSHIP OF DEINSTITUTIONALIZATION TO THE CONTINUUM OF COMMUNITY SERVICES FOR HANDICAPPED CHILDREN



It becomes obvious that these funding patterns have financially strengthened the continuum approach, without supporting family-centered services.

It is, therefore, important to closely analyse the implications of basing a service system on a continuum of different residential and educational environments. This continuum, which is so widely accepted, has evolved, in part, because of a national commitment to develop less restrictive alternatives to institutions. Alternatives that are based on more conscious, positive belief systems than have previously existed. In general, if this continuum is compared to what previously existed, when there are few if any alternatives to the institution, it is easy to agree that progress has been made. We have

recognized that disabled citizens have a right to much less restrictive living conditions.

For example, it is true that having your needs met by living in a group home in the community is better than having to live in a large segregated institution. Such an alternative is a less restrictive environment. It tends to be more integrative and consistent with the developmental model.

There are, then, several positive characteristics to a continuum of environments:

1. The continuum of environments could be so comprehensive that there are no "gaps" in the community service system.

Each of these environments is said to have "a place" on the continuum. Any state or community that has a wide enough range of these environments can be assured that all of its disabled citizens have an environment which is "matched" to their current functioning level.

2. It allows the client to move through the system as he/she grows and develops. Initially a client is placed in an environment which "matches" or is suitable to his/her current functioning level. As clients progress and gain new skills they can move or "graduate" to a less restrictive setting. Without a continuum of environments, this upward movement would not be facilitated.
3. A continuum is more cost effective. Proponents of the continuum argue that a continuum of environments is more cost effective than a service system which relies largely on the institutional model. Those clients who have shown sufficient progress can move from the institution to less costly settings such as group homes, clustered

apartments, or independent living situations (Hitzing & McGee, 1976).

The negative implications of the continuum are largely a result of the following basic misconception:

> A handicapped child must have his or her needs met by placement in a specific, usually "special", environment rather than by being provided an appropriate array of services that involves parents and family as the core of the delivery system.

It is true there have been many positive trends over the last decade: the re-establishment of the consitutional rights of all disabled citizens; the creation of more innovative community service alternatives; a ten percent decrease in the instituional population; and the vitalization of a national consumer advocacy movement.

However, there are also some dangerous trends within the continuum approach which are due to the fundamental misconception cited above.

1. Different groups need different environments - A continuum of environments is based on the belief that different groups or types of disabled citizens require different kinds of environments. We frequently hear that the "new role" of the institution is to be a state resource center, a setting where the multi-handicapped child or adult should live. By developing a role as the primary service setting for persons with severe disabilities, institutions are attempting to ensure their continued existence and future growth.

   Group homes are emerging as "the" residential environment for moderately and severely disabled children because many people assume they cannot be served in more independent or integrative settings.

   Nursing homes, or "crib" homes, have become the basic residential solution for children with special medical needs.

An indication of this trend is that it is now common to read of planning procedures which attach various levels of disabilities to different degrees or types of restrictive environments. This approach results in such statements as:

> "based on our current population of "x" number of severely handicapped individuals, we will need to develop "y" number of group homes".

2. Disabled persons must "earn" their way through the system. A major danger inherent in the concept of a continuum of different environments is that it tends to place the major burden of integration on the disabled person, rather than on the system. For example, it is common to presume that a severely disabled child must be institutionalized until he or she is "ready" to move into or "graduate" to a less restrictive community environment. Entrance and exit criteria for the child are usually developed for each of the different environments. A classic example of this negative aspect in education can be seen in the toilet training requirements set for entrance to some programs.

   In places where supportive services do exist, there is no reason why even a severly disabled child could not be supported in a family setting. Rather than requiring that the child be ready, the community planners and providers should analyze the needs and resources of the handicapped child and family, and then mobilize all the resources and services necessary to maintain the child in this setting.

3. Cost - A comprehensive continuum of community environments requires a tremendous expenditure of funds in the form of capital construction, major renovation, etc. Many states are investing millions of dollars

in institutional construction and renovations. This is often done under the guise of developing "more normalizing" environments within the institutional model (Hitzing & McGee, 1976).

At a community program level, these negative trends have resulted in:

1) systems developing with rigid program limitations that cause duplication, gaps and irresponsible planning.
2) permanent fractures of family systems by out-of-home placements and education in accessibility.
3) isolation of educational and residential services from the community mainstream.
4) financial support of family resource systems on temporary grants because of the long-term financial priorities of institutional and out-of-home alternatives.
5) artificial service needs are created that are based on funding availability rather than being shaped by families' growth and change as developmental/ecological systems.

The ultimate result of a rigid continuum approach is that families with handicapped children are forced to support programs of poor quality. Consumers continue to be uninformed and isolated. The existence of unresponsive and rigid community programs are viewed as preferable to none at all!

Reforming and redirecting the current continuum of community environments to emphasize family resource systems will only occur if fiscal and programmatic priorities are changed.

This would require the development of an alternative community service model that is based on the family as the core of the delivery system. Flexible and individualized programs must be organized into a model array of services. It is this alternative approach, or service array of family resources that will be discussed in the next section.

3.2. Model Array of Family Resource Systems and Supports for Handicapped Children and their Families

The current service continuum of community environments has resulted in only partial integration of handicapped children. This has had continuing institutional funding patterns that create entrenched disincentives to family centered service systems.

Today, we are at a crossroads in the development of programs to support rather than to supplant the families with handicapped children. (Skarnules, Cass, 1976). All families are faced with the reality of substituting social institutions for family responsibility that has been lost in the current continuum approach.

The current continuum of residential environments ranges from very restrictive to less restrictive environments, from institutions to individualized placements. In order to move from reliance on a continuum of different community environments, it will be necessary to develop a broad array of integrative service alternatives.

An array of family resources and supports must develop a network of services to handicapped children and their families. It is necessary to focus on the role of the basic value system of the community in the development of such a array. This focus should lead communities towards the development

of arrays of services (not continuums of different, segregated environments) necessary to enable a handicapped child, regardless of the severity of handicap to remain within his or her family.

Funding priorities and long-term cost benefits must be carefully measured and evaluated in terms of a more comprehensive implementation of the foundation principles of community development to insure the complete recognition of a family's roles as consumer and core of the community system.

In brief review, the foundation principles include:

-normalization (age and culture - appropriateness);

-developmental model (individualization and integration); and

-human and legal rights (least restrictive alternative, maximum growth environments).

Application of the foundation principles in the development of a systematic array of services and resources for families with handicapped children must include several critical elements to insure recognition of family roles. Four of the critical components or cornerstones of such a community array of services can be characterized as follows:

CORNERSTONE/COMPONENT	EXAMPLES OF APPLICATION
1. Meaningful consumer involvement	. consumer coalitions . monitoring teams . consumer councils . parent support groups . personal self-advocacy
2. Generic agency development	. community orientation and education . traditional agency re-direction (eg, foster care and adoption) . generic development and sponsorship of specialized programs (eg toybraries and regional resource libraries, homemaker-home health aid programs, Cooperative Extension Agents)

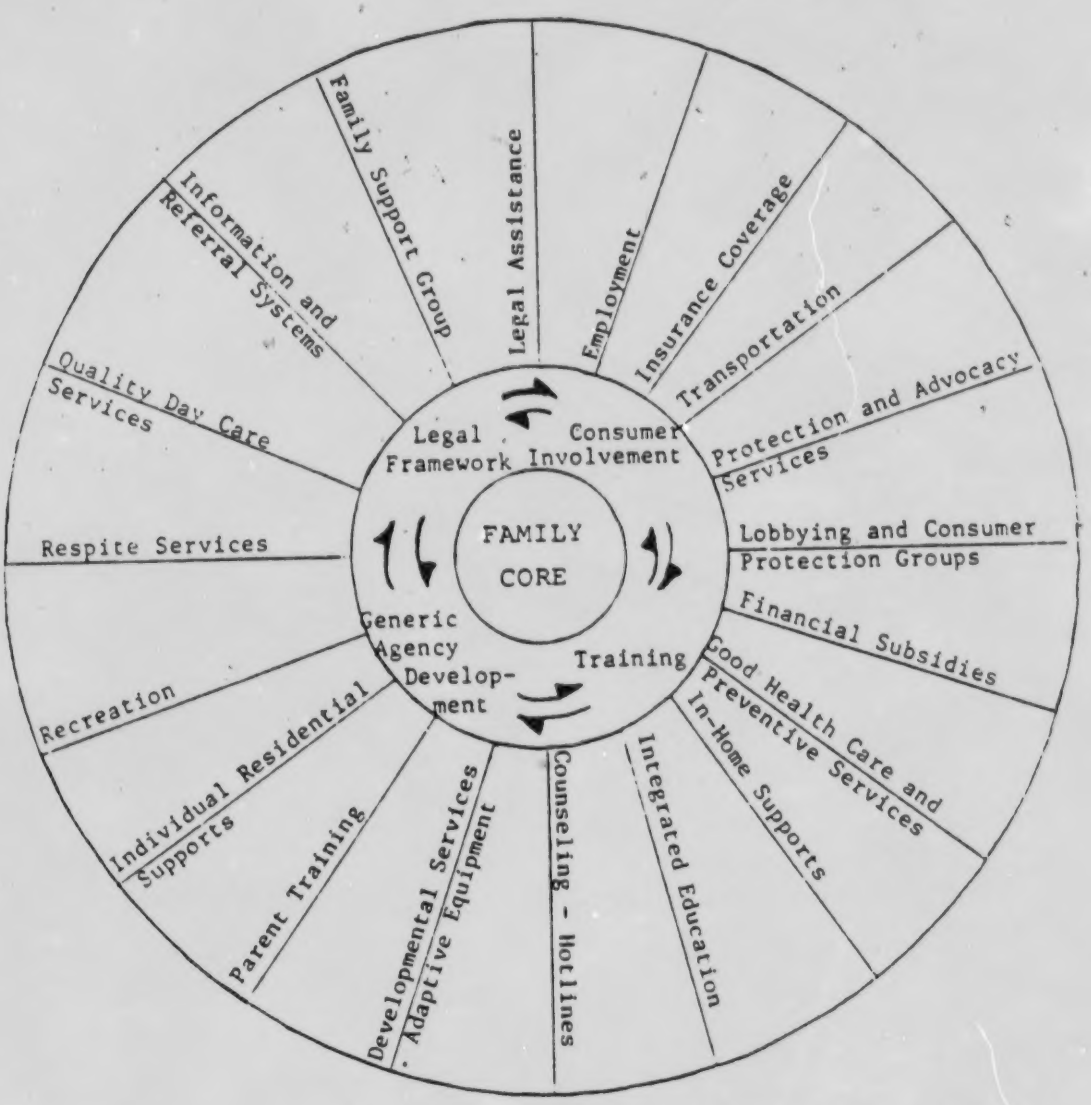
3. Legal Framework	. legislation and financing . funding and regulatory mechanisms . systematic insurance and administrative procedures . standards and accreditation
4. Training	. formal personnel preparation and orientation . specialized skill training . community education and information programs . parent and sibling training

If a community does not include these four critical components or cornerstones when developing a service array, the service program developed will likely not survive the perennial funding issues or resolve typical programmatic barriers (Cass, 1979).

Community programs that are based on array of services approach will have the following general characteristics:

1. integration into community mainstream
2. provided in-home as well as out-of-home
3. planned as well as crisis-oriented
4. part of a comprehensive community service network
5. short-term as well as long-term
6. individualized and responsive to changing needs and resources of the family or family member (CASS, 1976)

The array of community resources and support services for handicapped children and their families can be illustrated as follows:



MODEL ARRAY OF FAMILY RESOURCE SYSTEMS AND SUPPORT SERVICES FOR HANDICAPPED CHILDREN AND THEIR FAMILIES

Actual descriptions, profiles and characteristics of this model within a specific community setting depends on a number of additional local variables that can be categorized as follows:

a) value premises and community attitudes;

b) community program and agency management models;

c) availability and accessibility of potential resources;

d) regional economic, political and financial characteristics (demographics)

e) cultural vaiables;

f) state funding priorities and financial patterns of support.

In order to individualize this model array of services and supports, a community must first analyze the resources and needs of the handicapped child, his or her family and the community's available resources. This should be done at two levels: survey of consumers' resources and needs; and an inventory/review of the community service network. The information can then be incorporated into a planning process with the family to develop the kinds of support services needed. This planning process is not any different than that of an Individual Program Plan or Individual Educational Program.

It can be simply illustrated as follows:

Community Planning Guide for Implementation of Model Array of Family Resource Services

Step 1 - Mobilization of Planning Team

- provide orientation on background/issues
- clarify purpose
- develop general goals and strategies
- assign tasks for subsequent steps

Step 2 - Identification of Resources and Needs

- community inventory
- consumer survey
- research of issues, programs, etc.

Step 3 - Assessment of Step 2 Information

- list resources and needs (consumer and community)
- present other information
- review background information
- prioritize potential areas of development

Step 4 - Analysis of Step 3

- identification of barriers and obstacles, and other community realities
- list potential resources for barrier removal or minimization
- consensus re: final ranking of development priorities
- selection of priority area and level of intervention

Step 5 - Action and Implementation

- development of implementation strategies (goals objectives, and tasks)
- assignment of tasks
- implementation of plan

Step 6 - Evaluation and Monitoring

Instead of describing the specific components of the family resource service system model array that a community might develop, the following examples illustrate the variety of options that a community might consider:

FAMILY SERVICES NEEDS, POSSIBLE RESPONSES, AND MANAGEMENT MODELS

NEED STATEMENTS	POSSIBLE SERVICE DELIVERY RESOURCES AND RESPONSES	SAMPLE COMMUNITY SERVICES MANAGEMENT MODEL OPTION
1. Parents divorcing - request temporary live-in to clean and babysit with three children, one of whom is deaf and blind.	- Professional homemaker to care for home. - In-home resource to train (teacher) homemaker and assure life-space continuity.	Department of Social Services Visiting Nurse Association Homemakers, Home Health Aid Agency RSVP Program Community Developmentally Disabled Agency Trained sitter
2. Developmentally disabled child returns home in full-body braces from hospital; mother is 7 mos. pregnant, threatened premature delivery. Two other siblings.	- Father and grandparents learn lifting, turning and general care skills. - Skilled homemaker visits regularity in preparation for mothers absence.	Visiting Nurse Association Hospital in-home team Department of Social Services Homemakers Grandparents
3. Parents unable to toilet train 7 year old developmentally disabled child - entrance to special education program requires acquisition of toileting skills.	- In-home trainer - Toileting devices - Parent training - Physical evaluation of child.	Community college Generic Agency Clinic Special-Education Department of school Pilot Parent Community DD Agency
4. Developmentally disabled adolescent with multiple physical handicaps moves in with grandparents while parents on extended trip.	- Environmental design specialist to provide temporary devicing (tub, ramps, etc.) - In-home teacher to provide program continuity and train grandparents - i.e., lifting, carrying, feeding, exercise. - Temporary part-time in-home assistance (e.g., 2 hours/day). - Alternative transportation to day program.	University Engineering Dept. RSVP Carpenter Visiting Nurse Association Homemakers, Inc. Metro transit or cab
5. Elderly parents inquire about estate and will preparation - Expressing extreme concern about future of developmentally disabled adolescent child should they die.	- Provide list of attorneys, insurance agents, or bankers. - Create access to parents who have coped effectively with similar planning.	Local ARC BAR Association Bankers Association Business and Professional Association Pilot Parents Protection and Advocacy Agency Community Office of Aging

6. Developmentally disabled child, extremely hyperkinetic, sleeping in parents room with door barricaded to keep him from wandering. Parents totally exhausted and seeking permanent institution.	- Provide out home short-term, goal specified placement and parent training - Gradually return child to home as behavior changes and provide for intermittent respite care	Community mental health agenc Local D.D. Service Agency Crisis Services out of home Pilot Parents

(Skarnulis, CASS, 1976).

The critical factors in designing an array of family resources services are both the resources and needs of each family. A survey of potential service consumers does not have to be complicated or take a long time. The most important aspect of designing a consumer survey is the inclusion of questions related to family resources as well as questions regarding needs. A simple survey can give planners critical information about service types, fees, and consumer profiles. The following is a sample of questions used in a consumer survey that has been used with over a thousand families across the United States to plan in-home services.

CASS - CONSUMER SURVEY

1. What do you do when you need to leave your son/daughter with someone?

   I leave my son/daughter with/where (relatives, immediate or extended family; neighbors or friends; residential facility; foster care home, board and care home; sitters, if you check sitters, please indicate fee paid; other).

2. I have not left my son/daughter with anyone because:

   I have not found anyone willing to provide needed services; I have not the available persons were qualified; my son/daughter has too many problems; my husband/wife will not allow it; I cannot afford available services; other.

3. Have you ever used any relief care or home support services available through local community agencies?

4. In what kind of situation have you used these services? (planned, e.g., for a vacation; weekend off; crisis or emergency; both; other).

5. If the following services were provided, please indicate how you would rate them. (Needed, Not Needed, Uncertain/More Information Needed)

   a. Trained in-home support personnel to provide specific and specialized programs and/or training for my son/daughter.
   b. In-home support training for parent (myself/spouse) and/or other family members.
   c. In-home support personnel to provide sitter care for my son/daughter.
   d. In-home support personnel to provide companionship for my son/daughter.
   e. In-home support person to provide homemaker of home-health side services.
   f. In-home adaptive equipment or architectural barrier removal, modifications, etc.
   g. Temporary out-of-home sitter care service (less than 24 hours)
   h. Temporary out-of-home companionship for son/daughter.
   i. Temporary out-of-home living arrangement and/or services (less than 14 days).
   j. Temporary out-of-home living arrangement and/or services (15-30 days).
   k. Self-help support group for parents and/or son/daughter (e.g. Pilot Parents, Association for Retarded Citizens, People First, United Cerebral Palsy, National Society for Autistic Children, Epilepsy Foundation of America, etc.)
   l. Family counseling (e.g. ministers. social worker, therapists, mental health clinics, etc.)
   m. Medical/genentic counseling.

6. Would you <u>use</u> these relief care or home support services if they were provided?

7. Considering <u>only</u> the services you checked in Number 5, indicate your ability to pay for them. (Yes, Totally-Yes, To Some Degree-No)

8. How do you feel these services should be paid for? (I should pay for this service; a public agency should pay; I should pay, with some help from a public agency; other).

9. When would you be most likely to use/need respite services? (Evenings; weekends; weekdays; holidays; vacations; summer; other)

10. Approximately how many hours each day would you use/need these services? (Less than 4; 4-9 hours; more than 9)

11. Approximately how many days each month would you use/need these services? (Less than one day; 1-3 days consecutively; 5-7 days consecutively; 7-10 days consecutively; 11-14 days consecutively; more)

12. What are some barriers or obstacles you might encounter in obtaining the services you need? (Money; family schedules; transportation; services needed are <u>not</u> available; no information on services available; lack of confidence in personnel providing services; other; none)

(CASS, 1978)

There must be safeguards and guarantees that the service system will modify programs so that the h ndicapped child and his or her family can have their needs met in the least restrictive setting possible. Any deviation from this approach must be viewed as a major compromise with more positive solutions timelined for development and implementation. Such compromises should always be looked at as a function of needs or deficits of the system. Compromises should not base on family problems.

Community service systems have not progressed to the point where there is no longer a need for the out-of-home alternatives currently available. Communities have not yet developed the supportive services and resources needed by all handicapped children and their families to live in their natural home environments. If there is to be a significant change in the way that community services for handicapped children and their families, planners and advocates must seriously question the very existence of the agency-centered continuum approach instead, they must demonstrate committment and active support of the development of the family-centered array of family resources and supports.

In the next section, we will discuss how the continuum approach has affected the development of one aspect of systems (temporary supports and respite services) and how this parallels the current status of consumer involvement.

4.0. Current Status of Family Resource Services: The State of the Art in Temporary Family Support Programs and Respite Services.

There is no comprehensive community-based system of family resources and temporary support (respite) services for handicapped children in the United States today.

Approximately 200 different local programs provide some type of temporary family support services across the country. While these programs represent different geographic areas and cultural groups, serious gaps exist in temporary family support services for non-Anglo families with marginal incomes who live in inner city or isolated rural areas.

The current programs are operated by a wide variety of agencies, professionals, parents, volunteers, and coalitions. The programs are administered in a variety of ways. Because of local funding and regulatory patterns, they are usually reflective of other types of programs in the same state. Private non-profit organizations are the most frequent program sponsors.

The staff of the programs are usually high school graduates who have received 16 hours of orientation and training or less. There is a growing trend throughout these programs to utilize community training and certification programs, such as area community colleges and National Red Cross programs. The state of Washington has been a leader in developing competency-based training for in-home staff. Their program provides 40 hours of training as part of its statewide Home Aid Resource Program.

Fees for the different kinds of services vary according to the communities in which these programs operate. They typically use sliding scales and subsidies based on a family's ability to pay.

The total budgets for these programs are usually smaller than other community-based programs, with total budget averages of less than $20,000 for a fiscal year. For family resource programs that are <u>not</u> facility-based, the budget totals are usually far less. This is consistent with the current status of other individualized community living arrangements across the country, (such as foster care and individualized living arrangements).

When compared to fiscal priorities that continue to emphasize large group homes and institutions. (Morrell, 1978).

Despite the current barriers and disincentives to the development of family resource programs, there are, nevertheless, some exciting and promising examples of activities and programs that illustrate positive developments in family resources for handicapped children and their families in communities across the country (also see Report of President's Committee on Mental Retardation, 1979). Here are several examples from our own experiences:

- the state of Washington has a statewide network of Home Aid Resources that is capable of immediate response to crisis and planned situations for developmentally disabled consumers and their families, within their own homes.
- in Utah, a Cooperative Extension Project was funded by the State Legislature to establish a statewide network of Cooperative Extension Agents. They work in the homes of families with handicapped children, providing training, direct services, coordination and resources.
- a parent-to-parent self-help and support called Pilot Parents works in Nebraska, and other states to set up similar consumer support and self-help groups.
- Family Services of Kalamazoo, Michigan, supports a Parent Respite Care Cooperative where parents themselves arrange for and exchange services with each other.
- The Visiting Nurses Association of Dallas, Texas, has a reimbursement program where families hire, supervise, and pay their own in-home support staff.

- Coalitions of consumer groups in Minnesota, Maryland, and California have effectively introduced legislation aimed at funding family support services.
- A specialized home-based project for developmentally disabled consumers and their families in Georgia has been merged with a generic community service agency.
- Coalition, advocacy and active networking in Louisiana has resulted in allocation of over ½ million dollars in Title XX money for Respite Services.
- A homemaker agency in New York has started a project of home-based support for families with parents who have multiple sclerosis and their families.
- The Kansas Children's Service League has a cooperative program of temporary family supports in cooperation with a local Association for Retarded Citizns.
- The Respite Program of the San Diego Association for Retarded Citizens provides sitter and companyion services for families with handicapped children when they attend conventions and conferences in the San Diego area.
- The Archdiocese of Denver recruits temporary respite homes and providers through parish associations.

At the same time, there are still a significant number of the programs developed that continue to be variations of limited companion services and/or tied to established residential facilities and foster care homes. Some of the recurring problems in this kind of program

development and implementation are:

- narrow focus of progam area;
- inconsistent service delivery and accessibility to consumers;
- lack of programmatic monitoring by funding agencies, consumers, and the community at large;
- low financial priority placed on non-facility based services;
- absence of community education and generic agency development;
- lack of formalized agency policies and procedures;
- short term funding (usually via grants and contracts) with little or no development of long-range funding strategies.

Finally, the temporary family support programs that have been discontinued or are under-utilized have two common features. The first is financial instability due to short term funding arrangements. The second and most critical factor appears to be that the services designed and delivered were <u>not</u> the services wanted or needed by the families themselves.

5.0. Current Status of Consumer Involvement

Supporting the individualization of resources and returning service control to families is not as easy as continuing to support the current system that substitutes formal social institutions for family responsibility.

Meaningful consumer involvement often requires changes in general agency attitudes and specific program philosophy. It can be interpreted to mean "giving up" the power structure that is currently controlled by various professional and agency boards, task forces, committees and volunteer activities.

Consumer involvement at these levels is not usually viewed as an equal partnership with the human service planners and providers who design and implement the services that the consumers end up receiving.

The Carnegie Council on Children report on the status of families in this country has examined this issue in the broader field of all services for children. Their report, All Our Children, notes "...Traditionally, people who provide services, at least those publicly funded, (including contractors), have had to account to their bosses, not their clients, for how well they are doing their job...a father has very little to say in how his daughter's day care center is run, even though he may know more about the center's shortcomings and successes than the bureaucrat to whom they are supposedly being reported...".

Examples of this attitude can be seen daily at a variety of levels. Consumers are forced into "slots" and "openings". Individual identity is lost in the jargon that defines families as "units of service" and refers

to parents with phrases like "'Mom feels..'" and "'Dad' seems to think..." while brothers and sisters are referred to as "sibs...".

The current status of consumer involvement in the development and delivery of services to families with handicapped children is consistent with the continuing policies that emphasize models that change the families rather than the community service systems.

During the two year operation of our (CASS) national grant to study respite services for people with developmental disabilities, approximately 500 families were surveyed. Families often mentioned examples such as the following as being directly related to the issues of consumer involvement -

- Parents are restricted to clinic waiting rooms while their children are taken to therapy programs that parents could and often should participate in.
- Families are denied access to their records and other information related to the treatment of their children.
- Program planning meetings with families are held away from home at times convenient only for staff.
- Families are left to coordinate their own services from multiple sources because agencies refuse to cooperate.
- Multi-handicapped children are placed in residential programs far from their homes because of lack of transportation and in-home support services.
- Agencies refuse to develop individualized residential programs (in-home services, alternative living

arrangements and foster homes) because it would threaten existing out-of-home residential programs and potentially result in loss of income due to "unfilled beds".

- Parents are asked to write support letters for proposed projects that they know nothing about.
- Professionals on national boards are reimbursed for travel expenses while parents on the same boards are without child care or financial support for their involvement.

We do not mean to imply that current programs are always inappropriate or intend to neglect consumers. We do, however, mean that the current focus and design of community programs tends to reflect a general trend to depersonalize individuals and to fragment rather than support families.

The current status in funding source inflexibility and the continued support of out-of-home placements emphasizes the critical need for changes in community attitudes and types of service delivery.

6.0. Barriers to Implementation of Model Array of Family Resources and Support System.

There is a number of significant barriers to the effective mobilization of resources to meet the needs of handicapped children within their family environment in an integrated community. All of these barriers tend to reinforce the existence of restrictive environments, prohibit integration and create disincentives for family-centered services.

Today, most agencies and community service programs have a considerable investment in facility-based programs that are agency-centered. The agencies

need financial reimbursement for services delivered even if they are not appropriate for the consumers in order to cover the cost of facility maintenance and administration.

The result has been an incredibly entrenched bureaucratic system of financial and program disincentives at both state and federal policy levels that channel resources into social institutions that are not supportive of families despite their demonstrated cost-benefit (BAO, 1977, 1979).

There are signs that things are changing. A few states, notably Arizona, California, Louisiana, Massachusetts, Pennsylvania and Washington) have begun to fund plans aimed at developing a more comprehensive array of services for supporting families of handicapped children. Federal commitment and participation from the field of services for handicpped persons, however, has lagged even further behind.

Major recommendations for changes in national policy and program strategies must recognize that the development of innovative techniques and new systems of service delivery can never be enough.

1. The federal government, while providing 91 separate programs related to retarded citizens, has failed to unify these programs into a force that creates quality programs. Often one federal thrust diminishes the impact of another. For example, Title XIX monies have been used to support institutions while at the same time Title XX monies tend to support return to community life.
2. State and local elected officials are often caught in the middle of conflicts between various self-interest groups.

There are powerful groups which lobby for the interests of separate programs, programs which often have conflicts of interest.

3. Very few "hard" facts are known about either the costs or benefits of family-centered services. Cost figures are generally so vague that they have little impact on decision makers. Little has been done to identify costs on a per person, per family, per service basis.
4. Quite often consumer advocacy groups are divided in their efforts. For example, in one state the state association for retarded citizens is currently supporting a massive construction plan for the state's institutional system while a number of other local associations are planning to return all their currently institutionalized citizens to their home communities.
5. There has been little systemization of the major factors which make up a comprehensive integrative community service system. The typical community service program with its group homes, and developmentsl centers does not represent a comprehensive continuous service delivery system. Service alternatives have often emerged in a haphazard fashion rather than a step, planned effort to develop integrative alternatives.
6. As stated before the major barrier to development of quality family resource programs lies in our conceptual approach to program development. It seems that some people literally <u>cannot conceive</u> of severely multi-handicapped children living, working

going to school in normal settings.

Now there is a more difficult and in a sense more important challenge. We must convince parents, advocates, and professionals that hendicapped children have a basic right to the opportunity for full involvement in their community. It is not a question of whether the approach will be successful. We must make it work, it must be successful.

7. Even in those communities where services are beginning to focus on supporting the person in the natural environment, little is known about managing such a dispersed service system and maintaining quality of services. For example, a community which plans to integrate all disabled citizens is hard pressed to develop an effective management system to control such a dispersed service system. What population base is necessary to support such a system? Who monitors quality? How can the different federal, state and local funding sources be combined to provide a solid, enduring funding base which will be necessary for continued operation. (Hitzing and McGee, CASS, 1977).

7.0. Recommendations for Change:

A. Program Level: A Model for Training Families to be Consumer Advocates

According to one advocate with a handicapped daughter "....the informed parent is the effective parent...."

Changing from the role of object (passive recipient) to controller and full participant requires a mobilization of community resources and redirection of financial support for all families.

Returning control to families and recognizing the change in their roles as consumers has many benefits besides just that of cost benefit. This approach and redirection can:

- increase the likelihood of program continuity throughout the different environments that a child lives in each day.
- create opportunities for families to learn to effectively control their own home environment as well as the general community.
- result in the equal participation and investment of both families and service agencies through a cooperative network of community services with innovative techniques that are both flexible and accountable.

Effective consumer control is based on recognition and acceptance of the family as a responsible system with many components within a consumer role. Although the characteristics of the components of the family's role as a consumer may and should differ in emphasis and importance a family at any point in time, they can generally be described as follows:

(1) trainer/teacher of specific intervention techniques
(2) monitor of service and program accountability
(3) service broker and controller
(4) service broker and controller
(5) program monitor and reporter of provider competence quality
(6) parenting model for professionals and other parents
(7) community educator
(8) program/systems advocate for agency direction and legislative development

(9) community developer and neighborhood organizer.

There are many strategies and techniques that agencies and professionals could use to train families to be effective consumer advocates.

(1) organize, support and advocate for development of parent organizations and natural helping networks that provide resources, information, supports and self-help groups. This strategy has already been successful with families with histories of child abuse, parents of handicapped children, family health cooperatives, and community services for older people.

(2) design and implement programs of preparation and training for parents and family members that include functional intervention techniques and self-reporting systems.

3) develop and implement programs that include techniques to train families to monitor services and analyze their community support system (using inventories, access checklists, service systems evaluation tools, etc.)

(4) support and lobby for legislation and funding that emphasize the development of concrete/basic home-based supports (homemakers, sitters, equipment, repair services, etc.) as well as intensive social and educational in-home programs.

(5) develop checklists and other measures for evaluating competencies, performance and accountability.

(6) design and implement reporting and feedback systems for inter-agency communication.

(7) assist the implementation of consumers councils to monitor community service programs and oversee community planning.

This type of model for a coordinated consumer-training program has not yet been organized or implemented in the field of services for handicapped persons. It could be part of a broader consumer program, such as the National Coalition of Neighborhoods, Common Cause, or even the Gray Panthers. Nevertheless, it cannot be successful without the support of broad national policy reforms and the implementation of new strategies to support all families, including those families of children with handicaps.

Fragmentation and confusion of federal intent has resulted in policies and procedures that continue to look better in writing than in actual practices and service delivery. The Reports of the National Children's Defense Fund (1976), Carnegie Foundation (1977) and the National Commission on Mental Health (1978) have documented similar barriers to family supports. Both have called for a national committment to federal programs that support community systems where families (natural or otherwise) are the central core of service planning as well as deliver.

Development of such federal programs would likely involve the restructuring, redefinition and ultimate reform of existing federal programs. This would require drastic changes in the focus of the existing policies, regulations and funding strategies of the current federal deinstitutionalization mandate.

This new federal committment must be based on the basic assumption that all handicapped persons, regardless of age, can live and be served within integrated community settings. Programmatic interpretation of this committment should result in comprehensive development of flexible community-based family resource services for all handicapped children and the prevention of institutionalization or permanent displacement outside of a

family environment. It can no longer be assumed that a handicapped child needs institutional or congregate placement simply because he or she cannot be maintained in the natural family unit.

Divorce, death, and medical crisis are all examples of situations that may result in a necessity for out-of-home services. Innovative adoption and foster-care programs have clearly demonstrated the viability of a "family" oriented approach and the important role of a stable natural home environment for the well-being of children. (Child Welfare League of America, 1979). Foster and adoptive homes also need similar supports and family resources. While cost benefit comparisons with institutional placements can sometimes (but not always) be made, the major issue is the right of handicapped children to grow up in families that have the resources and supports to provide for their needs.

The issues involved in developing family resource policies and strategies for handicapped children are not different than those needed to support all of the children of the United States. According to the Carnegie Foundation (1977), changes in national policies and services to families must be based on a new set of principles that will include standards to measure:

- universal access
- racial and economic integration
- convenience and coordination
- parent participation
- utilization of paraprofessionals and volunteers
- emphasis on prevention and family integrity.

In summary, the Carnegie Report described a national program of comprehensive policy to support children and their families that include the following service areas:

1) jobs and flexible working conditions for parents
2) guaranteed minimum income level for all families
3) Integrated networks of family services that stress prevention and are monitored by local consumer councils
4) national health insurance and networks of community health systems based on existing health agencies
5) improved legal services and protection.

The Report recommended that these activities be systematically included at several levels:

a) within federal policy (where intent is translated public into regulatory financial priorities) that are interpreted into
b) local services for consumers.

Finally the Carnegie Report noted that a national program to support children and their families would require a cooperative network of families and their community support system.

7.0. Recommendations for Change:
B. National Policy and Strategies

The growth and development of community-based family resource systems and support services have been hampered by service barriers or obstacles at both state and national levels that are characterized by:

- agency isolation which results in the development of programs that have no access to information from other local, regional and federal levels;

- absence of federal and state commitment to planning community-based service systems that have respite services and family resources as a primary priority.

Current community-based service programs are not in a position to provide adequate resources for providing needed leadership because:

- systems are narrow rather than comprehensive in scope;
- budget and staff limitations limit the resources available to programs;
- programs are localized and often unknown to persons in need of information;
- there are no regional, state, or national mechanisms for accessing or disseminating information regarding model family resource programs, management approaches, funding strategies, etc.

The following is a set of recommendations for a National Strategy to support families with handicapped children that is consistent with those of the Carnegie Foundation. They are primarily based on issues identified by participants at the First National Conference on Temporary Family Supports and Respite Service Systems for developmentally disabled persons and their families (1978). In summary, such a National Strategy would include:

1) identification of a major Federal Bureau that is specifically mandated to support consumer-centered services for Families (Family Resources Bureau) and contains a specialized department to deal with the issues concerning handicapped children and their families.
2) formation of a National Coalition for Family Resources with an elected National Board made up of consumers, parents, advocates

and other family representatives.

3) introduction of federal and state legislation that supports family subsidy programs where families themselves can financially control services and supports provided (with a major focus on in-home and alternative living arrangements).

4) development of a cooperative political base for mobilizing full-time advocacy efforts for family resource programs within different consumer groups, federal and state agencies, Congress and other national groups (e.g. National Children's Defense Fund, the Carnegie Foundation, etc.)

5) generation of major funding support for national studies that will assess the impact of current federal policies and programs on the development and administration of family resource programs and their relationship to the family environment.

6) establishment of a national clearinghouse of Family Resource Services advised by the Board of the National Coalition that would:

- maintain a communication network;
- develop more effective mechanisms for dissemination of a federal and state level information to local grass-roots consumer organizations;
- coordinate and participate in regular multi-level conferences, meetings and hearings;
- compile and disseminate annual resource directories of family resources and temporary supports;

- provide/develop a program of technical assistance, resources and training for federal agencies that will sensitize them to the needs of families with specific emphasis on the impact of these services on the family system, (e.g., decreased institutional placements, maintenance of natural family environments, etc.)

7) design and implementation of model Family Ombudsman Projects and Family Advocacy programs at both state and national levels.

8) advocating for the development of federal or state legislation, regulations and voluntary standards for family resource programs and service providers.

Final Implications

Implementation of these national policy recommendations would reflect many of the following policy and implications identified by Hitzing and McGee (CASS, 1977) in an earlier analysis of integrative support services for consumers with developmental disabilities -

1) recognition of full and legal rights through programmatic implementation of the principles of the least restrictive alternative. By focusing on and meeting the needs of the child, the family, or the community in natural environments, the least restrictive alternative will have been attained. The concept of "least restrictive" will cease to be relative and arbitrary. Instead, it will presume the natural home setting to be the least restrictive. The removal of the handicapped child from the natural setting or the placement of an institutionalized person in an artificial life environment

will be seen as an abridgement of the person's rights and a major compromise by the service system.

2) The full recognition of the handicapped child as a developmental being. By both physically and socially integrating the handicapped child into natural community environments, a child, despite his/her type or degree of handicap, will be looked upon as a developmental person, capable of growth. Developmental growth will not be seen as requiring a segregated environment. Instead, it will occur with individualized supports and resources in integrated community settings controlled by consumers and their families.

3) The further development of the principle of normalization as supportive of families, cultures and environments. The principle of normalization will be recognized as both a process and an outcome. Over the last decade normalization has helped us focus on "establishing, maintaining or supporting culturally normative behaviors." However, the current approach to developing services have not always used means that are a culturally normative as possible. There will be broad recognition and acceptance of the attitude that persons with disabilities do not have to earn the right to be integrated into the community mainstream or to remain part of his or her family.

4) Supporting, not supplanting the natural home. The first response to serving a handicapped child will not be to assume that outside placement is needed. Instead, agencies and planners will ask

"How can we help keep your family intact." Supporting the child in his or her family environment will be accomplished through a wide array of services and creative service options that are flexible and individualized.

5) Integration will be the responsibility of the service system and not the handicapped child and his or her family. If we are dedicated to the support of families with handicapped children, then it will be necessary to understand that integration of the person depends more on the type and quality of the community service system rather than on the person's needs and individual "progress".

6) Current funding patterns which emphasize permanent facilities and long term out of home programs will be reversed. Society cannot afford both a continuum of agency-centered programs (such as state institutions, group homes and nursing homes) and a full array of family resources and support services.

There must also be a basic committment to the fundamental principles of consumerism and family integrity.

It requires more than tokenism and "lip service". It means developing strategies and activities at both policy and program levels that are aimed at changing the community service delivery system and professional attitudes, as well as providing support through intensive and innovative techniques.

The development of family resource services that are flexible and individualized to meet a family's needs is a long neglected challenge. Re-

sources for handicapped children and their families must be part of a broader movement to support the well-being and integrity of all children and their families. A national policy to support families, however, continues to appear remote in view of current structures and funding patterns.

The most creative service options that will be developed in the meantime will still be those developed in spite of funding limitations by communities that recognize the change is not the family's responsibility but is shared by the systems that are supported by the taxes of parents and the presence of their children in those programs.

CHAPTER 4

Supporting the Handicapped and Their Families in Rural Areas

Alan M. Hofmeister

Overview

During the two-year period, from 1974 to 1976, the Exceptional Child Center developed and validated a service delivery model for working with severely handicapped children and their families in rural areas. This project was funded by the Bureau of Education for the Handicapped (Hofmeister & Atkinson, 1976). The project met the objectives that were set in that we were able to demonstrate that we could deliver services capable of increasing the skills of severely handicapped children in rural areas through the involvement and support of the family as the basic instructional agent.

During the process of developing and validating this service delivery model, a major problem was encountered. We had established an extensive information system using a combination of personal contacts via field staff, a toll-free telephone service, and a parent resource library. When requests for help came in from local service agencies and families, we found ourselves unable to meet certain needs because of the nature of our funding source. We were restricted to serving severely handicapped children of school age. Requests for help for preschool handicapped and their families, from the adult handicapped, from the mildly handicapped, and from handicapping areas not covered by the Bureau of Education for the Handicapped, e.g., Multiple Sclerosis, had to be rejected. In conducting Project TELEPAC, it became obvious that any delivery model that focuses

on such a narrow range as severely handicapped school-age children will encounter major cost-effectiveness problems. It also became obvious that any service delivery system that was setting out to meet a variety of needs of a family in their environment would have to be rather careful of affiliations with most of the existing service programs, in that most service programs are funded for specific age or disabilities categories. The idea of setting up a totally new service delivery system also presented problems in that the cost of building new administrative and communication networks and the process of public education would limit the funds available for direct service families.

Problems in Meeting Needs in Rural Areas

In providing services to rural areas, we have encountered a range of problems, including:

1. Lack of community development resources.

   Because of the sparse population base, the development and functioning of local advocacy groups is restricted. Without such groups an important source of ideas and political pressure to develop and support local programs may not exist. In more populated areas a critical mass of advocacy personnel is easier to assemble and maintain.

2. Lack of general information resources.

   A rural family in search of information on such matters as handicapping conditions and home intervention procedures will often have difficulty locating resources to provide such information. Again, the sparse population base and the

associated problems of time and distance restrict (a) the development of local centralized sources of information, and (b) communication channels to disseminate information in response to specific requests.

3. Lack of treatment program coordination.

   The development of intense and coordinated intervention programs is limited by availability of professionals to help coordinate and develop locally available treatment resources.

4. Technical assistance services.

   The few professionals who do work in rural areas experience considerable difficulty in finding technical assistance to help them solve local problems. The distance from the other model programs, the limited availability of in-service training, the lack of advanced back-up services all contribute to the isolation of the professional.

5. Timely intervention.

   In many situations time is a critical element in rural and remote areas. The professional needing technical assistance to meet pending funding deadlines, or seeking advanced help for a pressing family problem finds that while help may exist somewhere, such help may never arrive in time to be of assistance.

The Cooperative Extension Program

In searching for an approach that would help solve some of the previously listed problems, we decided to explore the Cooperative Ex-

tension Service. The Cooperative Extension Service, with more than 3,000 offices throughout the nation, remains the only system with a statewide organization, national affiliation, and local support base, which is dedicated to the transfer and use of knowledge to solve problems. The system appeared to have a great amount of flexibility. The framework is in place to deal with a wide range of national, state, and local problems. The Cooperative Extension Program also had an impressive record. It had proven its ability to improve the quality of life of those it had reached in rural areas. It has an excellent record in youth development programs, the improvement of rural homelife, and in community development. In recent years the Cooperative Extension Program has widened its scope to urban areas as new problems, such as energy conservation, were being confronted.

Despite the breadth of cooperative extension programs in the areas of agriculture, natural resources, environment, home economics, youth activities, and community resource development, there had been little evidence of a substantial coordinated effort to meet the needs of the handicapped and their families.

The Tennessee "County Agent for Children's Program" (Miller et al, 1976) was one of the few programs within the national cooperative extension network that did focus on the needs of the handicapped and their families. While evidence of concern for the handicapped had been encountered in several other states, this has not been translated into systematic programs.

The Structure of State Cooperative Extension Programs

Most cooperative extension programs within a state have the following administrative pattern:

The County Agent

Spearheading the work of the Cooperative Extension Service at the local level are the county extension agents. These agents live in the community, and most of their assistance is provided through meetings, demonstrations, workshops, short courses, publications, mass media programs, and follow-up consultation. Most Extension agents are from two broad fields (a) specialties in agriculture, and (b) home economists.

Program Aides

A recent addition to the county agent staff has been the program aides. Most of these are employed in the food and nutrition education programs to help supplement the educational services of the county agents' staff. They also work with the agricultural and youth programs. and the general educational components of extension.

State Specialists

Supporting and acting as resource personnel and consultants for the county agents are the state extension specialists. These specialists are usually housed at the state university.

In Summary

Those wishing to implement service programs for the handicapped should take into consideration the problems of (a) limited community development resources, (b) restricted sources of information and associated communication channels, (c) lack of professionals and the support

services for such professionals. The segregation of service by age and disability appear to have limited value in rural areas. Meeting the needs of the handicapped by expanding proven and accepted existing service delivery systems such as the Cooperative Extension Program appears to have considerable potential.

The Utah Cooperative Extension Program for the Handicapped

Using the argument that the Cooperative Extension Program was committed to the quality of life of all the families and, therefore, should identify a set percentage of its resources for the handicapped, an approach was made to the Vice President for Extension at Utah State University. We received enthusiastic support, and with that support, an approach was made to the State Legislature for pilot fundings to develop and field test a service delivery model to help meet the needs of the handicapped in Utah. The Utah State Legislature listened and granted $30,000 for the first year. This financial commitment has been continued, with cost of living increases added in each succeeding year.

To head the Cooperative Extension Program for the Handicapped in Utah, Dr. Glenn Latham was appointed jointly by the Utah State University Exceptional Child Center and the Utah State University Cooperative Extention Service. Goenn became the State Extension Specialist for the Handicapped. He traveled to each site to supervise and help develop the role of the extension aide for the handicapped.

Breadth of Services

As the model developed, some of the problem areas that were of initial concern were solved. A broad service delivery model was established. Staff were free to serve the handicapped without regard to age, level of disability, or the category of disability.

Local Community Orientation

The service delivery model had strong local community support in that the office of the county agent is jointly supported through federal, state, and local monies. The county agent cannot exist without the support of the local county commissioners. Local involvement was further enhanced by hiring as extension aides for the handicapped, local personnel. Having locally based persons, such as county agents, available is important in guiding program development. As Ginsberg (1969) has noted, the rural sociological structure is often very complex and "...may be based upon little remembered but nevertheless influential historical events focused on family conflicts, church schisms, and a variety of other occurrences which may deserve the status of legends" (p. 30).

In the early stages of the model, the staff tried not to force a given role or structure on the system, but rather try to be responsive to needs and develop roles and procedures consistent with needs. In the following section, these roles and procedures will be described in more detail.

Services Provided through the Cooperative Extension Program

Direct Services

Extension aides respond to requests from the field for help in

working directly with the handicapped clients and associated family members. They provide such basic help as teaching handicapped individuals to talk, walk, self-feed, dress, self-toilet, use impaired limbs, etc., and/or teach others, such as parents, siblings, extended family members, and volunteers to teach these skills to the client.

Assistance in the Coordination of Services

Experience to date has indicated that there are are a variety of services available to and needed by the client that are not being provided or used. The aide assists with the coordination of services to see that the client realizes the greatest possible benefits from all available resources. At the client's request, the aide will take the role as advocate or mediator for the client in interactions with agencies and service providers. Such advocacy interventions range from assisting the client in negotiating specific services from a state agency, to interceding on the client's behalf with creditors, e.g., physicians, to reduce and/or reorganize debts acquired by the client.

Acts as a Catalyst for Community Development

The State Specialist and the extension aides have been successful in assisting in the organizing of local advocacy groups, and supporting and developing leadership roles in advocacy groups by the handicapped and their families. Aides do not take formal leadership positions within the advocacy organizations they help develop. Rather, they provide ongoing technical assistance and support. Where local advocacy groups and resources are limited, the aide takes steps to awaken, alert, and motivate

the community to what needs to be done to improve the quality of life for its handicapped citizens and their families.

Information Dissemination

(a) Literature. As a senior staff member of the Exceptional Child Center at Utah State University, the State Specialist has access to a wide range of documents and technical and practical papers to disseminate in response to written and telephone requests.

(b) Parent Resource Library. The Office of the State Specialist maintains a resource library for the families of the handicapped. Contact and requests for information can be made through toll-free telephone lines, in person, through the mail, or via the the extension aides for the handicapped in the field. The library offers catalogs of its holdings free of charge to the handicapped and their families. Materials are sent at no charge and mailed with a prepaid mailer enclosed.

Toll-free Telephone Service

The office of the Specialist maintains a toll-fre (WATS) line that enables clients and professionals seeking information to call without charge. The line is monitored by a secretary specifically trained to respond to a wide range of requests. Requests that cannot be handled within the Exceptional Child Center are referred to the appropriate state agency. Any request that cannot be met at the time the call is made and has to be referred, is always followed up by a telephone call to the caller within 24 hours to inform them of the specific action that has been taken.

Training

The State Specialist has a major role in conducting in-service training for professionals, paraprofessionals, and community groups.

Consultant and Technical Assistant Role

The State Specialist and the extension aides serve as consultants to service providers and civic bodies. Other extension personnel provide information that would improve the quality of life to the hendicapped and their families.

Information Delivery

One of the major functions of the total Cooperative Extension network is the transmission of information. This information is done through the translation of the findings from research and program development efforts into practical vehicles capable of being used by the consumers. The problems of information translation for agricultural use and other activities, such as home food preparation, while sometimes difficult, do not present the problems faced by those preparing information for use by the parent of a handicapped child. The combination of problems faced by such parents is complex, and general suggestions will have limited value. Most workers consulting with families have found that giving a parent a list of simple general rules to follow has limited value. The hope for generalization to the parents' specific problems rarely occurs.

In order to combat some of the problems listed above, the Cooperative Extension Staff for the Handicapped use parent training packages as a major information delivery vehicle. These training packages represent

a systematized way of delivering specific instructional procedures related to high priority problems. The term "package" implies a self-contained and portable system. Everything that is needed for the parent to conduct intervention is usually included. Materials include step-by-step instructions for determining the present functioning of the child and the procedures for carrying out the instruction. The parent packages used have all been validated for use by paraprofessionals, and for many of the packages, the field-testing was conducted by having parents use the material by themselves, without pre-training. In short, the field-testing was designed to insure that the packages were able to make changes under field conditions with limited support services. Most of the packages were developed by the Outreach and Development Division of the Exceptional Child Center, Utah State University, and by Progect MORE, George Peabody College for Teachers.

Figure 1 (Training for Independence, 1979, p. 20) represents a sample page from a package. The highly specific nature of the materials is evident in this Figure. The key aspects of the instructional sequence, the correction procdures and appropriate reinforcement procedures, are included and specified. While the range of packages presently available is not sufficient to meet all the problems that will be encountered, the packages allow an extension aide to provide a wide range of useful information in a very practical form. For the extension aide new to the job, the packages also represent a major source of in-service training information. One of the major advantages of the use of training packages

LESSON 1 *Taking off a Shirt or Sweater*

Getting Ready

MATERIALS:
1. Oversized pullover shirt, T-shirt, or sweater
2. Learner's own shirt
3. Instructor's Chart
4. Learner's Chart
5. Pencil and crayons for marking charts
6. Reward badge

STEP A

I: (Put on a large T-shirt or sweater and stand in front of the learner.)

Watch me. I'm taking off my shirt [sweater]. (Use exaggerated movements and go through the stages, saying:)

Cross your arms.

Hold the bottom of your shirt at the side. Really reach around to the back.

I: Pull it up . . .

I: . . . up, up over the head.

I: Now pull one arm out.

I: Then pull the head out . . .

Figure 1: Sample page from Training for Independence, "A Program for Teaching Independent Dressing Skills"

with parents is that the same materials and procedures can be used with paraprofessionals and volunteers who have extensive responsibilities in rural areas (Horejsi, 1976).

Administration and Funding

The director of the project, Cooperative Extension for the Handicapped, also carries the title State Extension Specialist for the Handicapped. He is located in the Outreach and Development Division of the Exceptional Child Center at Utah State University. Although physically located within the Exceptional Child Center, the State Specialist for the Handicapped is regarded as a full-time member of the State Extension network and is responsible to the University Vice-President for Extension, as well as the Director of the Exceptional Child Center. The Project Director is responsible for the administration, supervision, and training of the extension aides located in the County Agent offices. To date, five aides have been trained and placed in the field. Funding for the project during 1978-79 Fiscal Year was as follows:

$50,000 awarded by the State Legislature to the Exceptional Child Center specifically identified for Cooperative Extension activities for the handicapped;

$ 6,000 from the University Extension Services; these monies were for both salaries and travel;

$ 7,000 from the Exceptional Child Center for secretarial support and travel;

$25,000 of CETA funds; most of these funds were received for some of the extension aides.

Present plans are for the Extension Service to contribute a larger share and possibly replace most of the CETA-funded positions. One of the advantages of using the community-based paraprofessional as basic in-field personnel is that access to federal manpower funds, such as CETA funds, is considerably easier than many other funding routes.

Present Status

The Cooperative Extension Project is still in an experimental stage. The different delivery vehicles, e.g., the use of local aides, and the relative emphasis among different objectives, e.g., community development versus individual casework, are constantly monitored to develop and determine the most effective use of available resources. In providing services to the handicapped within the Cooperative Extension model, federal guidelines and staff have been supportive. Similar support has been received at the state level. Response among county agent staff has varied. A few have had difficulty broadening their view of extension services to the notion that Cooperative Extension should be concerned with the quality of life of all families. Extension home economists have had no difficulty in accepting the idea of adding services that would meet the needs of the handicapped and their families. It is worth noting that many of the services that this project adds, also benefits the nonhandicapped. For example, many of the materials carried by the Parent Resource Library, such as those on behavior management, are applicable to parents of nonhandicapped children. The intention has not been to establish a set of segregated services, but rather a continuum of

services. Within this continuum, both the handicapped and the non-handicapped will find help.

Conclusion

To effectively meet the needs of the handicapped in rural areas, procedures should emphasize:

(1) The extensive involvement of local resources, e.g., the parent, the volunteer, and the paraprofessional;

(2) A highly adaptable program policy with considerable flexibility to accept a variety of handicaps and age levels. Even the term, "developmentally disabled", is too narrow in that it restricts populations such as Multiple Sclerosis from receiving services.

(3) Comprehensive support services to the professional in terms of technical assistance and in-service training.

(4) A range of service delivery procedures that are built on the notion that people need not be taken to a centralized site before receiving services.

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CHAPTER 5

M A N U A L

OF THE

PARENT RESPITE CARE COOPERATIVE

Written by: The Co-op Committee of Kalamazoo
Association for Retarded Citizens

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FORWARD -- A NOTE TO PARENTS

For most of us, daily care and management of a disabled child or adult is a demanding job. We want to do all we can for our disabled children, but our other children, husbands and wives, parents and friends, need us too. Without regularly planned time to rest and refresh, most parents begin to wear out.

Kalamazoo Association for Retarded Citizens has often pointed out needs for respite care services in the Kalamazoo area. Family and Children Services in serving families with mentally or physically disabled members, has seen parents become exhausted and family crisis develop when there is no relief from the demanding care.

With the backing of KARC and a group of other community services, F&CS submitted a grant proposal asking for federal money to start services offering several types of respite care so parents could comfortably leave their disabled child or adult for short periods. This grant was funded as of July, 1976 by the Developmental Disabilities program (through the Michigan Department of Mental Health).

The Parent Respite Care Cooperative is one of these services. It is a new idea and a new program. We feel it is based on "common sense". Families help each other, (using professional staff only as needed), with the care of each others' disabled children or adults. The funding pays fo for Family and Children Services to help parents organize and operate their own respite care exchange. KARC, as a group of parents of the retarded and disabled, sponsors the Co-op and cooperates with F&CS to make this program work.

This Manual has been written by the KARC Co-op Committee--parents of disabled persons. We have been guided by this question: "What do we want for ourselves and our children as we participate in the Parent Respite Care Co-op?" In answer, we have tried to set our policies and procedures to make it as easy as possible for parents to get together to give each other good respite care that they can trust.

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Part I
Background Information

OUR PURPOSE AND GOALS

The purpose of the Parent Respite Care Cooperative is to meet the part-time or short-term (2 weeks or less) respite care needs of disabled children or adults living in the Kalamazoo County Area with their families.

Goals of the program are:

1. To assist families of disabled individuals to function in a way that permits and encourages individual growth and mutual respect between family members;

2. To prevent the need for a family to use institution or foster care for the disabled family member;

3. To assist parents in operating a Respite Care Co-op with the sponsorship of KARC and the guidance of Family and Children Services;

4. To provide the opportunity for disabled family members to develop friendships with other families and their disabled and non-disabled members.

5. To provide opportunity for brother and sisters of disabled persons to become friends;

6. To provide opportunity for parents of disabled persons to share successes, problem-solving, and information of mutual interest;

7. To maintain readily available respite care parents can use regularly and can trust - the "break" needed by parents, disabled persons, and other family members.

* * * * *

WHAT THE CARE CO-OP OFFERS ITS MEMBER FAMILIES

For Parents:

1. Care of the disabled child or adult, provided on request, by and for parents who know and trust each other.

2. Respite Care without cost - paid for by care given for care received (no exchange of money)

3. Training and help by parents for each other in the care of each disabled person - so no parent feels afraid to care for the child of another.

4. Available professional assistance from the program Coordinator and Advisor or other community services.

5. Time for yourself - "a break" - to spend with husband or wife, with other children, on personal interests, or for family business.

6. Peace of mind - care to count on in an emergency.

For the disabled child or adult:

1. Visits with Care Co-op families who know him, like him, and enjoy seeing him grow.

2. New friends and new experiences.

3. Safe, healthy, understanding care.

For the other children and teens in the family:

1. Time alone with mom and dad - and parent attention all for themselves.

2. A chance to become friends with others who have disabled brothers and sisters.

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KARC - F&CS COOPERATION

The Parent Respite Care Co-op is:

Sponsored by: Kalamazoo Association for Retarded Citizens

Managed by: Family and Children Services of the Kalamazoo Area

Operated by: (and for) Parents of disabled children and adults

KARC is a group of parents, professionals and concerned citizens who have joined together to promote the general welfare of individuals in Kalamazoo County who are mentally retarded. Family and Children Services of the Kalamazoo Area is a multi-service family social agency. Both are funded, in part, by the Greater Kalamazoo United Way.

In the Care Co-op program, a parent or "consumer" group (KARC) and a professional social agency (F&CS) cooperate to help parents provide a Respite Care service for each other.

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THE CO-OP COMMITTEE

The Co-op Committee is appointed annually by the KARC Board as the policy-making body for the Parent Respite Care Cooperative.

DEFINITION OF TERMS USED IN THE CARE CO-OP PROGRAM

Developmental disability:

Defined by federal law as a disability that begins during childhood (developmental) years, before age 18. Specifically included as: mental retardation, epilepsy, cerebral palsy, autism and other neurological disabilities that resemble these and require the same treatment. (This same federal law designates funds to be used in each state for new services for developmentally disabled citizens. The Parent Respite Care Co-op is one of these services.)

Cooperative:

Group of individuals who join together to share the work of providing a mutually beneficial service. Service received is returned for service given.

Respite:

Time away for parents and other family members, to be used as needed for rest, pleasure, business, vacation, emergencies or time to spend with other children or family members.

Respite Care:

Short-term care by one Co-op parent for the disabled child or adult of another Co-op parent, to give respite or relief time. Care may be given either in the respite givers' home or in the disabled persons' home.

Respite care period:

Time during which the disabled person is given care in a respite care home while the parent is away. May be any number of hours or days within a range of from one hour to 14 days.

Requesting parents:

Parents who request respite care for their disabled family member.

Respite parents:

The Co-op parents who provide substitute care while the parents are away.

Respite care request:

Call made by requesting parents to the Care Manager requesting respite care for their disabled child or adult.

Sending parents:

Parents who send their child to another Co-op home for respite care.

Sending home:

The home of the sending parents.

Care recipient:

The disabled child or adult who receives care, so that his/her parents may have respite.

Credit hours:

Hours of respite given by a Co-op parent.

Debit hours:

Hours of respite care received by a Co-op parent.

Part II
Policies and Guidelines

POLICIES AND GUIDELINES

The following pages identify the official KARC policies for the Co-op project. They were developed and written by the Co-op project. They were approved as KARC policy in February of 1977, and have been reviewed and revised annually by the Co-op Committee.

To be consistent with KARC's standard of high-quality service in each of its projects, the Co-op Committee has developed the following policy guidelines using the following criteria:

1. To specify standards we would want for our children and with which we, ourselves, would be willing to comply.

2. To make policies and standards as few, as practical, and as simple as possible.

3. To give the guidelines enough detail to make the Co-op easily workable.

4. To follow common sense.

While each individual Co-op group will decide just how to run their own respite care exchange, the Co-op Committee has intended that their standards and guidelines should protect both the disabled person while receiving care and the parents when giving respite care.

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BECOMING A CARE CO-OP MEMBER

WHO MAY APPLY TO JOIN THE CO-OP?

Policy:

Any family that lives within the Kalamazoo County area and who has a mentally or physically disabled child or adult family member may apply for Co-op membership.

Procedure:

Interested families should contact the Parent Respite Care Co-op Coordinator at Family and Children Services, 1608 Lake Street, Kalamazoo, Michigan, 49001. The telephone number is (616) 344-0202.

HOW DOES A FAMILY JOIN THE CO-OP?

Policy:

To become a member of the Care Co-op, an applicant family must:

1. Agree to participate in the Co-op for a period of at lease one year; and

2. Participate in the Co-op according to the policies as set forth in this Manual.

Procedure:

Applicants sign a Membership Agreement stating that they are willing to comply with the policies listed above.

WHAT IS THE APPLICATION PROCEDURE?

HOW DOES A FAMILY DECIDE IF THE CARE CO-OP IS RIGHT FOR THEM?

Policy:

We intend that --

1. Each disabled person will receive respite care in a healthy, safe and caring home, and

2. parents will be able to take time out in confidence that their child or adult is receiving good care.

Therefore, the application process is planned to protect both the disabled child or adult who will receive care and the parent who will be giving respite care. It was set up to consider with the family whether, at this time --

1. The Co-op will meet their respite care needs, and

2. They are able to provide respite care for others.

As the family applies for Co-op membership, both the Coordinator and the family together will consider the following questions:

1. What are the family's needs for respite care? Could they be met by taking part in a Co-op?

2. What are the abilities, limitations, care needs, and problems of the disabled family member?

3. What are the strengths and limitations in the applicant family and home for giving respite care to others? How would providing respite care fit their life-style, family life and home at this time?

4. Does the home comply with the KARC Health and Safety Check List?

Procedure:

An application form is obtained from a Care Co-op member or the Coordinator (at Family and Children Services,(344-0202). It is filled out by the family and returned to the Coordinator. The Coordinator then meets with the parents -- once to discuss family respite needs and the care needs of the disabled person--and once in the home to discuss the possibility of the family providing respite care for other disabled persons. The family checks their own home using the Co-op's Health and Safety Checklist and discusses their findings with the Coordinator. The parents then read the Manual and discuss their questions with the Coordinator.

The family is welcomed as Co-op members when the Coordinator and applicant parents together decide that teking part in the Care would be mutually beneficial for this family at this time.

WHO SEES THE COMPLETED APPLICATION FORM?

Policy:

The application of a family for Co-op membership is always respected as a confidential matter. It is partly to assure this confidentiality that the entire application process is the responsibility of the Coordinator.

Procedure:

The application process takes place in the applicant's home or the Co-op Coordinator's office at Family and Children Services. Co-op parents never see the completed membership application form. Completed forms are kept confidentially on file in the office of the Coordinator.

HOW IS EACH CO-OP GROUP FORMED?

Policy:

Suggesting or helping to organize the particular Care Co-op group for which an approved applicant family would be best suited is the responsibility of the Coordinator consulting with the applicant family.

Procedure:

In forming a new Care Co-op group or assisting a family to join a compatible group, the following will be considered:

1. Geographical location of the family's home -- how far can the family travel for respite care?

2. Age-related needs of the disabled person; age preferences of each family in providing care.

3. Disability-related needs of the child or adult; and disability preferences of each family in providing care.

4. Other needs or preferences expressed by families.

WHAT IF A FAMILY NEEDS TO WITHDRAW FROM THE CO-OP?

Policy:

We ask that a family consider carefully before joining, and try to make at least a one-year committment to remain in the Co-op. This is because every member family is important in a Co-op; we all depend on each other to make our respite care work.

However, sometimes the situation changes or the unexpected happens. If a family finds that continued Co-op participation will be a problem for them, we ask that they do the following:

Procedures:

If possible, discuss the problem with the Co-op group and/or the Coordinator to see if it might be worked out within the Care Co-op without the family withdrawing.

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ORGANIZING THE CARE CO-OP

CO-OP OFFICERS AND THEIR DUTIES

Policy:

The following officers and their duties are considered necessary to enable each Co-op group to provide the best possible respite care with the least amount of time and effort spent in organization and operation.

Procedure:

Each Co-op will appoint a Co-op Chairman. The Co-op Chairman will, in turn, appoint a Care Manager, a Workshop Manager and Secretary.

Except for the Co-op Chairman who will serve for one year, the length of term of each officer is to be decided by the Co-op group.

The responsibilities of each of the Co-op officers are listed as follows:

The Co-op Chairman

1. Coordinates the Co-op organization and business.

2. Serves on the KARC Co-op Committee and keeps the committee informed about Co-op activities and services.

3. Acts as spokesman for the Co-op group.

4. Keeps a record of Co-op activities, number of participants; reports these regularly to the Co-op Committee and to the Co-op Coordinator as needed.

The Care Manager

1. Coordinates all respite care requests and arrangements.

2. Keeps a record of debit and credit hours and other respite care service information.

3. Arranges substitute care if respite parent needs to be away during an assigned care period or in the case of an emergency in a respite care home during a care period.

4. Informs the Workshop Manager about parent needs and suggestions for more workshop training sessions.

5. Records hours spent managing respite care exchange and reports to the Co-op Chairmam.

The Workshop Manager

1. Plans and manages workshop sessions (information and training) for Co-op members. This includes:

   --arranging time, date and place and informing Co-op group;
   --making physical arrangements, getting together any necessary equipment or supplies;
   --contacting and arranging with resource person when appropriate.

2. Plans workshops according to parent requests and any needs or problems seen by Care Manager.

3. Records hours spent arranging for and holding workshops.

THE CO-OP WORKSHOP

Policy:

Each Co-op group will have an active Co-op Workshop program. The workshop will serve to provide information and additional skills needed in giving and receiving respite care.

The Co-op Workshop is a basic part of the Co-op plan. All Co-op parents are expected to participate. Parents must attend the initial workshop sessions before giving or receiving respite care. The Co-op Workshop is designed to give each Co-op family the support and the help they may need to be able to comfortably care for other Co-op children or adults. We hope parents will also gain some skills that will be helpful in working with their own disabled family members.

The workshop is planned to:

1. Give each parent a time and place to teach the group the care and needs of his/her own child.

2. Prepare each family to provide respite care.

Procedures:

The Workshop Manager will plan and set up workshop sessions together with the Chairman and the Coordinator. The workshop plan includes group information and training sessions as needed and requested by Co-op parents, both before beginning respite care and continuing at regular intervals.

The number of workshop sessions, how often they are held, the time and the place and the content of each session will depend on the current needs of the Co-op group.

Sessions should be planned so that both parents can take part in the Workshop program (ex: alternate daytime, evening, weekend sessions, etc.).

Details of the workshop program will be worked out by each Co-op group for themselves.

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GIVING AND RECEIVING RESPITE CARE

Legal Questions Relating to the Co-op Respite Care Service

When the Co-op project first began, the Co-op Committee served as a task force to 1) develop the KARC policies and guidelines for the Parent Respite Care Co-op Program, 2) set the criteria and the application procedure for Co-op membership, and 3) write the Care Co-op Program Manual.

As the first Co-op group formed, the Co-op Committee was reappointed as a permanent committee of the KARC Board. This committee consists of four KARC members, plus the chairman of each Co-op group. The committee meets monthly or according to plan, based on the current needs of committee business.

The Committee continues to represent the KARC Board in dealing with the development, progress and policy-related problems of the Care Co-op Program. The Chairman of each Care Co-op reports regularly to the Committee about Co-op activities and services. The Committee serves as a liason between the Board and the Care Co-op Groups.

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THE PROGRAM STAFF

The purpose of the program staff--the Coordinator and agency support services-is: 1) to organize and manage the Care Co-op program, and 2) to provide advice or assistance as needed or requested by parents so that parents will have the support they need to form the Care Co-op group(s) and operate the Respite Care exchange.

The Coordinator is a social worker on the staff of F&CS. By agreement between KARC and F&CS she devotes 2/5 time (15 hours per week) to the Care Co-op program. She is responsible to the Executive Director of F&CS. She works with the Care Co-op program according to the guidelines mutually decided with the Co-op Committee (representing the KARC Board).

The responsibilities of the Coordinator include:

--Accountability for the Care Co-op program.
--Coordination between KARC and F&CS - meeting bi-monthly with the Co-op Committee about program goals, progress, and problems.
--Managing publicity and outreach efforts (often carried out with parents).
--Meeting with interested families (application process).
--Giving advice or assistance as requested or needed by parents exchanging respite care.

In addition, F&CS makes available to this Program: secretary (7½ hours per week), office supplies and printing, telephone and receptionist, and meeting space.

LIABILITY:

Policy:

All Co-op members will be required to have Homeowners (or renters) insurance and must carry liability insurance on their automobiles in case of personal injury or property damage during a respite care period.

The sending family's homeowners or renters insurance (liability) will cover any damage done by the care recipient. The homeowners or renters policy of the respite care family will cover any accidents to the care recipient in the respite care home.

The legally required Michigan automobile insurance will cover accidents to family members in their own or another car.

Procedure:

Each applicant is asked to indicate insurance coverage on the Membership Application form. Families without liability coverage will not be eligible for Co-op membership.

In addition, a WAIVER OF LIABILITY will be included in the Membership Agreement, to be signed by each Co-op member.

THE MICHIGAN CHILD CARE LAW

(Act 116 of Public Acts of 1973, Regulation of Child Care Organization)

Policy:

Under the law, the Parent Respite Care Cooperative is considered a parental exchange. As such we do not require a state child care license as long as we observe the following rules:

1. A respite care period for a child in a respite home MAY NOT EXCEED 14 DAYS. (Even one day over this limit is illegal without a foster care license).

2. Every individual request and arrangement for respite care MUST BE MADE WITH THE CO-OP AS A GROUP and not with an individual Co-op family. (If one family intended to be the primary provider for a child on a long-term basis, a license would be required.)

3. NO MONEY MAY BE EXCHANGED FOR RESPITE CARE SERVICES. (Any exchange of money would also invalidate insurance coverage for respite care).

The Co-op will remain within the law as a parental exchange through the following procedures:

1. No respite care will be given by one respite home to the same recipient for longer than 14 days at a time.

2. Every individual request for respite care will be made to the Care Manager who, as representative of the Co-op group, will locate a respite home and arrange for respite care. Care recipients may receive care from any or all of the Co-op families over a period of time.

3. Each family will pay for respite care received with respite care given. A record of hours given and received (debit and credit hours) will be kept by the Care Manager.

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THE CARE RECIPIENT'S TRAINING OR TREATMENT PROGRAM

Policy:

KARC strongly supports training and treatment programs for the disabled person. The Co-op will make every effort to continue the care recipient's normal routine during the care period.

Procedures:

1. Any necessary home therapy should be continued, even during one day of respite care.

2. Any out of home program should be continued, as appropriate, if the care recipient is in respite care for more than 24 hours (school, speech therapy, vocational training, etc.)

3. School transportation should be arranged ahead of time by the parent with the school district. (The school can tell you where to call.) When the school district will not transport the care recipient to school from the respite home the respite parents or other Co-op members may need to assist. Each Care Co-op group should set up a plan for assisting respite parents with transportation when necessary.

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SUBSTITUTE CARETAKERS
(When respite parents need to be away)

Policy:

When a disabled child or adult is receiving respite care there will always be adult supervision. When a respite parent must be away during a care period, only another Care Co-op parent or an adult family member (age 18 or over) may be used as a substitute caretaker.

Non-family teenagers may not be used to care for a disabled person receiving respite care. Respite family teenagers may be used only as short-term emergency back-ups (example: while arrangement is being made for an adult supervisor).

Procedure:

1. Non-emergency substitute care should be planned by the respite parent with the Care Manager and the sending parents prior to the care period. (Example: respite parents plan to be out of the home for one evening during a weekend respite care period.)

2. In case of an emergency in the respite care home, respite parent will notify the Care Manager, who will locate a substitute caretaker -- either a Co-op member to come into the respite home or another respite home or another respite home to take the care recipient.

3. A Co-op parent earns regular credit hours for substitute care given.

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ILLNESSES

Policy:

In the interest of everyone's good health, a parent may not send an ill person for respite care. Also, the family may not receive a child for respite care when a family member is ill.

Procedure:

1. If a child or adult is scheduled for respite care and becomes ill, or if a parent is scheduled to give respite care and a family member becomes ill, the Care Manager must be notified immediately and the respite care plan must be cancelled. If possible, alternate respite care arrangements should be made.

2. Each Care Co-op group should agree on their working definition of "illness". (For example: Is a child with a runny nose "ill"?)

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ACCIDENTS AND EMERGENCIES INVOLVING THE CARE RECIPIENT

Policy:

Each Co-op group must carefully spell out the exact steps to be followed by the respite care parents in the case of an emergency. These steps must include the following procedures:

Procedures:

1. A list of emergency telephone numbers and Co-op accident/emergency procedures to be followed during respite care must be posted in each Co-op home.

2. Accidents or emergencies must be reported as soon as possible to the Care Manager or a designated alternate. The respite parents and the Care Manager will decide together whether or not to contact the sending parent. (The individual Co-op group should decide exactly how severe an accident or emergency must be before sending parents are notified. Definite procedures must be determined.)

3. Accident Report forms will be kept in each care recipient's folder (which accompanies the care recipient to the respite home). A form is filled out by the respite parent and is discussed with the sending parent as soon as possible. The Care Manager collects any Accident Report forms monthly. Past reports are kept on file by the Co-op Coordinator.

4. Co-op parents must sign a medical release when leaving a child or legally incompetent adult in respite care. (If parents are unavailable, and no release is signed, the court would be asked by the hospital or doctor to appoint a temporary guardian.)

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CREDIT AND DEBIT HOURS FOR CARE GIVEN AND RECEIVED

Policy:

The Co-op will keep track of respite care given and received by each Co-op family by recording "debit" and "credit" hours.

Each family must maintain a reasonable balance between debit and credit hours.

Procedures:

1. An exact record (ledger) of debit and credit hours for each Co-op family will be kept by the Care Manager.

2. The Co-op group will agree on -- and set -- a maximum and minimum number of debit and credit hours that a family may accumulate. (Example: how many hours of respite care may a family use before being required to give care hours?)

3. A Co-op group may choose to credit the Care Manager with credit hours in recognition of time spent managing the relief care arrangements.

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RULES AND PROCEDURES OF THE INDIVIDUAL CO-OP

Each Care Co-op group will develop an easy to follow Handbook which will specify in detail the individual Co-op's operating rules and will tell, step-by-step "how we do it". This will be completed by each Co-op based on the policies specified in Part II of this Manual. Each group is free to adjust its operating rules according to what works best for its member families. The Handbook should be simple and easy to follow and should include the following areas:

1. Co-op group organization: What the officers will do, how they will be appointed, their length of term, use of business meetings, and how any Care Co-op business will be handled.

2. Co-op Workshops: How and when workshops will be held, how they will relate to parent needs and how Co-op members will take part.

3. Recordkeeping: The method for keeping track of care hours given and received by each Co-op member and of any other respite care information needed.

4. Respite care requests and assignments: What parents must do to arrange for respite care; and the system for assigning respite care.

5. Giving respite care: What may and may not be expected of respite parents based on "Policies" in this Manual and according to Co-op group agreement.

6. Receiving respite care: What may and may not be expected of the sending parents (by Co-op group agreement).

7. Emergency procedures: The exact steps to be followed in the case of an emergency --

   --involving the care recipient, or
   --involving the respite family during respite care.

8. The Handbook: to specify procedures for making additions or revisions and for distributing the Handbook. (Procedures should be revised by the Co-op group as needed. Any suggested policy changes should be discussed with the Co-op Committee.)

CHAPTER 6

RESPITE CARE

A "How-to" Manual
by Cary Carron

INTRODUCTION

RESPITE CARE: A LIFELINE FOR PARENTS OF THE DEVELOPMENTALLY DISABLED

Parents who have sons or daughters with developmental disabilities have been deeply hurt and desperately need healing of mind and spirit. The many perplexing questions and problems associated with developmental disabilities are overwhelming and bewildering.

In most families, the disabled child or adult places an extra burden of care on mothers and fathers. The unending responsibility for care, encouragement, training and daily life routines all falls to parents already carrying heavy burdens and often lacking the time, energy, and the propensity to set up support systems not easily accessible. With little relief from daily responsibilities, frustrations, feelings of isolation, physical and psychological exhaustion steadily mount.

Families with a disabled member need to feel they are not alone. The emergence of humanism and individual dignity as a way of life has led to an almost incredible awakening of the public conscience concerning developmental disabilities. Society has begun to appreciate and face its responsibility for the developmentally disabled person. It is now generally accepted that the resolution of the problems precipitated by the presence of a developmentally disabled person in the home is no longer the sole responsibility of the family or any single profession, discipline, or agency. It is one requiring the cooperative efforts

and the pooling of knowledge, information, and resources of many, all directed to resolving the problem.

The intent of this manual is to provide a profile of a three-year old respite care service which will also serve as a "how to" model. It is written in the hope that other agencies interested in developing such services will not have to spend time on obstacles already overcome by this Project. The manual will also demonstrate how Church and State can work together to improve the quality of life for all.

We cannot hope to dispel pain for families with disabled offspring, even if that were desirable. This manual is written in hope of dispelling some of the loneliness and confusion by offering a credible model of family support.

In the end, we can hope that the pain of others can teach us to be compassionate and caring human beings. At least, presently, it is a deeply human condition in which we have been permitted to share.

THE CHALLENGE

Previous efforts to provide respite care services by the five Associations for Retarded Citizens in the Denver Metropolitan area had met with little success.

In an attempt to serve families with a developmentally disabled member, three members of the Board of Directors of the Denver Association for Retarded Citizens met with the Director of the Ministry to the Handicapped of the Archdiocese of Denver in January, 1976. At this meeting the challenge was presented to the Archdiocesan Director to develop and implement a respite care service.

The challenge was overwhelming! The Archdiocesan Director asked for a week to consider the proposal before making a decision to accept or reject the challenge. Factors to be considered seriously before making a decision were:

1) the lack of success of previous attempts to develop respite services;

2) the Ministry to the Handicapped had not been a direct service provider;

3) funding for the respite care service was not possible from the Ministry to the Handicapped budget; and

4) the staff of the Ministry to the Handicapped was too small to provide direct services.

Factors having greater impact on the decision were:

1) the needs assessment by Denver Association for Retarded Citizens clearly revealed that respite care was a priority

of parents (it ranked 4 on a priority list of 21);

2) respite care services would be a vital supportive service in keeping the family unit intact;

3) respite care service has a great potential to prevent the institutionalization of a disabled family member; and

4) a fact that we run into time and again is that every program is aimed at the developmentally disabled person because his/her need is so visible, while the families, who are also wounded have no way to alleviate their needs.

PREPARATORY PHASE

Once the decision to accept the challenge was made, a new concept and approach had to be developed to avoid the pitfalls which had contributed to the lack of success of others who had attempted to provide respite care services.

Realizing that churches offer a vast, generally untapped, volunteer resource, the Archdiocesan Director was convinced that the success of this endeavor would be ensured if this compassionate, empathetic, and caring human resource were utilized. In February, 1976, to establish a sound base for respite services, the following strategies were employed:

1) the development of a working relationship with Denver Catholic Community Services, utilizing their expertise in the area of Foster Care as well as their contacts with the Social Concerns Committees in parishes. This resulted in the assignment of a full-time liaison staff member of Denver Catholic Community Services to work with the Archdiocesan Director;

2) the formation of a Steering Committee whose function was advisory and policy making. The Steering Committee was comprised of a representative from Denver Association for Retarded Citizens, Arapahoe Association for Retarded Citizens, Denver Catholic Community Services and the Ministry to the Handicapped, as well as parents from two families with developmentally disabled offspring;

3) a series of meetings were held. Member agencies assumed the following responsibilities as groundwork for a pilot program:

   a. The Ministry to the Handicapped developed the pilot program.

b. DARC and the Ministry to the Handicapped developed necessary forms to be used in the pilot program.

c. DARC and the Ministry to the Handicapped developed the Orientation session for respite care providers.

d. Denver Catholic Community services and parents developed the Screening forms used to evaluate the respite care provider homes.

e. DARC and Ministry to the Handicapped, in conjunction with the Center for Legal Advocacy, developed contracts for respite care, researched licensing procedures of provider homes and investigared aspects of insurance and liability.

POLICIES

At the April 22, 1976 meeting the following policies were set forth:

1) the Archdiocesan Director of the Ministry to the Handicapped will be the Respite Care Administrator and Coordinator (at least for the pilot program).

2) There shall be no Committees or Boards other than the Steering Committee. The Respite Care Administrator/Coordinator shall be responsible for the total program management.

3) For the pilot program, each Respite Care Home shall be limited to just one severely handicapped at a time.

4) The disabled individual needing Respite Care must live in the community with parents.

5) Respite Care must respond to emergency cases. Determination will be made by Respite Care Administrator/Coordinator.

6) Limit age to under 30 years.

7) Criteria for accepting requests from parents/legal guardians, and eventual placement shall be determined on the compatibility of the provider and parents/legal guardians.

8) Orientation sessions and meetings involving Respite Care will be held at the Archdiocese of Denver Ministry to the Handicapped Office.

9) All respite care providers shall carry insurance.

10) All Respite Homes shall be screened prior to using the home for respite services. The Screening Committee shall consist of a Masters in Social Work from Denver Catholic Community Services, Respite Care Administrator/Coordinator, and parents from two families with disabled members.

11) The Center for Legal Advocacy determined that a respite home need not be certified if the respite care placement is less than three consecutive days.

12) Each respite care provider shall have three letters of reference on file in the Ministry to the Handicapped Office.

13) The Respite Care Administrator/Coordinator shall negotiate the service fee.

14) Fees for Respite Care Services shall be paid directly to the provider.

PILOT PROGRAM

RATIONALE:

Many parents of mentally retarded and other developmentally disabled children or adults are often faced with the problem of finding short term care, one to thirty days, maximum, for their sons or daughters. (For the pilot program short term care refers to no more than three consecutive days.) This short term care is needed for many reasons:

1) illness in family

2) doctor's appointment

3) to enable a family to take a vacation

4) to help a family cope with an emergenty

5) simply for relief or "respite" from the often heavy demands of daily care.

For most families, the only viable choice is placement in an institutional setting. This is often difficult to accept as the handicapped person would be faced with the problem of adjusting to a setting that was much different from home. Forced into this solution makes it harder for parents to feel comfortable when they find placement necessary. Obviously there is a need for an alternative which would more closely approximate the warmth, familiarity, and structure which was part of the handicapped person's home. It is this need that we are attempting to meet in the development of a Denver Archdiocesan Respite Care Pilot Program.

PROCEDURE:

We see our preparatory work for the pilot program in this sequence:

1) identify Respite Families with the assistance of the Social Concerns committees of Notre Dame and St. Mary Parishes.

2) identify Families wanting Respite Service in conjunction with Denver Association for Retarded Citizens.

3) "Orientation" or educational series for Respite Parents is held. This is designed according to the needs and interests of the Natural Parents.

4) When a request for Respite Service is received, the Respite Care Administrator/Coordinator arranges a visit into the home of the Natural Family in order to determine the handicapped person's suitability for respite care. The Coordinator considers the handicapped person's needs and then matches the most appropriate Respite Family that will meet these needs.

5) a pre-placement visit is arranged with the Natural Parents, handicapped persons, Respite Family, and Coordinator at the respite home, affording the families an opportunity to become acquainted. During the pre-placement visit the dates of the respite service are finalized and the agreement for respite care is signed by the Natural and Respite Families.

SUPPORTIVE SERVICES:

The Respite Care Coordinator will be on 24 hour call should an emergency arise or should the Respite Family be in need of supportive services. Denver Catholic Community Services should be available to the Coordinator because supportive services must be an integral part of the program.

ON GOING EVALUATION:

After the actual visit, the Administrator/Coordinator contacts both families and records the Respite and Natural Parents assessments on the Placement Log. The Logs will be kept on file. An attempt will be made to utilize the same home if the Respite Service was successful.

MEDICAL RESPONSIBILITY:

The Natural Family assumes medical responsibility. The Archdiocese of Denver does not.

FEES:

The Natural Parents will be asked to pay the fee of $10 per day the first two days and $5 for each ensuing day. Hourly scale for less than overnight care will be $1 an hour. Inability to pay the fee will not restrict the availability of this service. If the parents aren't able to pay, one of the three agencies, Denver Association for Retarded Citizens, Denver Catholic Community Services, or Ministry to the Handicapped shall subsidize the cost with monies available to Denver Association for Retarded Citizens, or from alternative sources of funding for Ministry to the Handicapped. We feel that it is necessary to charge a fee so that families will not consider this service to be a charity.

PLACEMENT INELIGIBILITY:

We generally will not place handicapped individuals who require one-to-one care or those with severe behaviorial problems, since this would require too much of the Respite Mother's time. We must avoid placing the Respite Mother in a situation where she might have to neglect her own family.

Also exempt from placement, at least for this pilot study, is the elderly retarded or disabled. This does not mean that if the pilot is successful we should not explore the possibility of doing something for those individuals over thirty years.

PROBLEM AREAS

Consumer Interest

During the summer months of 1976, response to the respite care program by parents of developmentally disabled persons was indeed disappointing. The program efforts met with many calls of inquiry but no requests for service. We interpreted this lack of response not as opposition to supporting respite care, but rather, as a reluctance to become involved in a program with which they were not too familiar.

In retrospect, this lack of response was probably due to three assumptions made by parents: 1) the respite service would be provided for only Catholic families, 2) the Archdiocese would probably proselytize the disabled person, 3) they would not get their hopes up for a service which had such a bad track record and which again would probably be unsuccessful.

The Respite Care Pilot Program was launched, literally, in November, 1976, with the request from a social worker for emergency placement. Finally, with the documentation of this respite care placement, the program's credibility began to grow; indeed, it had escalated! Extensive use of the service was imminent.

SERVICE EXPANSION:

The publicity and popularity of the Respite Care Pilot Program had become widespread. In addition to Denver and Arapahoe Associations for Retarded Citizens, Adams County, Aurora and Jefferson County Associations for Retarded Citizens became active members of the Respite Care team in January, 1978.

It was the consensus of this new Respite Care Team that the Archdiocese of Denver, because of its freedom to operate in all ARC counties in the immediate Denver Metropolitan Area, be the agency to provide the expanded service. Thus, the Archdiocese of Denver Respite Care Service, responding to the respite care needs of the Denver Metropolitan Area, was founded.

FUNDING:

With the rapidly increasing case load, other issues began to surface. Funding became the most critical issue. Directly related to funding was the need to employ a full-time person to coordinate respite services.

In an effort to generate more funding, the Archdiocese of Denver submitted a grant proposal to the Colorado Developmental Disabilities Council in February, 1977. The grant was awarded in June, 1977 for FY 1977-78.

Funding Facts:

Colorado Developmental Disabilities Council	$12,655.00
Cash Match (Five Denver-Metro ARC's Archdiocese of Denver)	4,835.00
	$17,040.00
Actual Budget FY 1977-78	$33,826.61

The grant afforded the following:

1) half salary for a full-time coordinator (the Archdiocese provided the remaining half);

2) operating expenses; and most importantly

3) financial assistance to help needy families to pay for the service.

It is important to note here that only on rare occasions was it necessary to subsidize the entire cost for the service. Almost every family using the service contributed something toward the cost, even if it were twenty-five cents per hour.

NATIONAL DEMONSTRATION MODEL

The Archdiocese of Denver Respite Care Project had gained recognition. In January, 1978, a representative of the Center for the Development of Community Alternative Support Services (CASS) visited the program. As a result of this on-site visit, the Project was chosen to be the National Demonstration Model for Community-Based Respite Services Systems

With this distinction, the Project Director had the responsibility of conducting workshops for the First National Conference on Temporary Family Support Systems for Developmentally Disabled Persons held in Betheseda, Maryland, May 3-5, 1978.

It was gratifying that the Archdiocese of Denver Respite Service System brought added respect and recognition to the State of Colorado. Indeed, Colorado was accepted as the pioneer and leader in community-based respite services!

CHILD PLACEMENT AGENCY:

The widespread publicity and popularity of this Respite Care Project brought it under the scrutiny of the Colorado Department of Social Services. After several meetings with members of the licensing department, it was decided that it would be necessary for the Ministry to the

Handicapped office to purchase the services of a Masters of Social Work from Denver Catholic Community Services to become a Child Placement Agency. In February, 1978 the Archdiocese of Denver Ministry to the Handicapped office became a child placement agency.

CERTIFICATION OF RESPITE CARE HOMES

The issue of certifying all homes providing respite care became an issue in February, 1978.

Since its inception, it had been the practice of the Project staff to certify homes providing respite services for longer than three consecutive days, complying with the recommendation of the Center for Legal Advocacy.

Discussion and negotiation on the licensing problem has continued from February, 1978 to the present, August, 1979.

Central to the difference of opinions held in regard to certifying all respite homes is the determination made by the staff of the Social Services Division:

1. The Archdiocese of Denver, Ministry to the Handicapped is a licensed child placement agency and hold out to the parents of developmentally disabled children specific places which they have deemed appropriate for the care of those children on a short term basis. The issuance of the certificate will ascertain that indeed the home does meet the licensing requirements and the home is appropirate for the care of developmentally disabled children.

2. If at some future time that foster care is paid for through the County Department of Social Services, such homes will have to be licensed. It seems to be unequal treatment if a home were able to care for children without a license until such

time as the fee for care came from a County Department of Social Services.

3. This State has no definition of occasional care of children in a family foster home. We believe it is improper to establish a definition for occasional care in a family foster home which cares for developmentally disabled children. Occasional care is defined in case law as irregular and infrequent care. The care described might be infrequent in that it is once a month, but it might be regular in that it is the fourth weekend of each month.

In response to Social Services stance, the Colorado Respite Care Consortium believes that respite care homes are not typical foster homes because parents maintain all their rights while the child is in respite care. To further support the Consortium's position, the parents/guardians approve the respite home as an appropirate setting before their son or daughter is placed. The Colorado Respite Care Consortium will continue its efforts to resolve this issue with the Colorado Department of Social Services.

APPENDIX 1

COLORADO RESPITE CARE CONSORTIUM

PHILOSOPHICAL POSTURE:

Respite Care represents a concern for the families with developmentally disabled persons living at home. These families are often the walking wounded, and a program which allows them occasional or periodic time off from the demands of caring for their handicapped person creates a much healthier atmosphere for the whole family, as it helps keep some light at the end of the tunnel for a parent who might otherwise feel that the world rests on their shoulders.

It is a fact that we run into time and again, that every program is aimed at the handicapped person, because his/her need is so visible, while the families, who are also wounded, have no way to alleviate their needs. We have found that a major benefit of respite care is to emphasize that it is serving primarily the family rather than the handicapped individual. This has tremendous psychological power to heal, (because it gives the family the right to be hurting and in need), and any healing in the family is a direct benefit to the developmentally disabled member of that family.

We sincerely ask your official support for respite care.

THE PROBLEM:

Families with developmentally disabled members have varied problems

with which they must cope. There are times when the tensions become so great that it becomes necessary for the developmentally disabled individual to be temporarily out of the home. Due to a lack of alternatives, parents in crisis are often forced to initiate institutionalization for their son or daughter.

Until very recently the emphasis has been to provide service for the developmentally disabled individual and not his family. It is this fact which has precipitated the urgent and critical need for family support services, namely respite care.

ISSUES:

Tensions and crisis may develop from:

1) the extended hospitalization of a parent;

2) serious marital disharmony;

3) severe acting-out by the developmentally disabled member;

4) parents becoming overwhelmed with the care and responsibility of the developmentally disabled person; or

5) chronic health problems of the handicapped person, et.

ALTERNATIVES:

An alternative way to respond to such crisis, ease the tensions in the home, better prepare the developmentally disabled individual to function at home or in the community, counsel families, and improve the quality of life for all is to provide respite services and counseling.

DEFINITION:

Respite Service is appropriate, short term temporary care, provided in a variety of settings, for the care of the developmentally disabled

for a period of time, on a regular or intermittent basis to: (1) meet planned or emergency needs of the family and (2) restore and/or maintain harmony within the family unit.

This service is directed toward maintenance of the developmentally disabled person in his family home, although in some cases respite services could be utilized by other residentaial providers for similar reasons. Maximum stay per client shall be limited to no more than 45 accumulated days unless the need for a greater number od days can be documented.

LEVELS OF PRIORITY:

Three levels of need which would qualify a developmentally disabled person/family for service are defined below.

1. A family unit may experience a need when it encounters an immediate personal or family crisis. The crisis will either already have occurred or be imminent, and unless assistance is made available, the family will suffer irreparable harm. The magnitude of such a crisis may be so great as to cause severe emotional, physical, and/or mental stress to members of the family.

Examples include: death of an immediate family member; divorce or severe marital problems within a family; hospitalization or serious illness of a family member (one largely responsible for the care of the developmentally disabled person); severe emotional physical, or mental family stress; the birth of a baby; or temporary loss of residential placement for a developmentally disabled individual.

2. Another need is considered to be more preventive in that stress relief might decrease the chance of a more serious crisis in the future. During the period of stress, the presence of the developmentally disabled person in the home may magnify the problem the family is facing and, if not checked, might lead to a greater problem in the future. In such instances, the best course may be to remove the developmentally disabled person from the family environment until the family's problems have been resolved.

In allowing the family an interim period of relief, the problems that first caused placement may sometimes be alleviated. For example, the techniques that family relief provider may use in dealing with a developmentally disabled person's behavior problems or lack of skills can be shared with the family prior to the individual's return home.

Examples of these types of crisis may include: the death of a close friend or relative; a businss trip which takes the supportive member away from the home; a family move in which the developmentally disabled individual is not to be involved until the move is completed; family stress; problems with other children in the family; or, temporary loss of a "babysitter".

3. A family makes many sacrifices to meet those special needs of a developmentally disabled individual who requires virtually constant attention. If there is actual or anticipated difficulty in securing relief, parents may sacrifice their social lives, feeling compelled to meet all the needs of the developmentally disabled person. The resulting tension may not allow for approximate attention to the needs of other

family members. Examples would include a much-needed vacation, time off, or non-residential supervision for part of a day or evening.

TARGET POPULATION (STATE WIDE):

Respite services will be provided for developmentally disabled persons with any age limitations.

PROJECTED CONSUMERS TOTAL NEEDS (STATE):

Needs

1) Short Term Temporary care

2) Counseling

3) In-home support

Existing Resources to meet the needs:

Respite Services Projects:

1. Denver Archdiocese - National Demonstration Model

2. Mesa County ARC

3. Pueblo ARC

   a. Respite Service
   b. Counseling
   c. In-Home support

Cannot identify any other community-based resources

CHAPTER 7

MENTAL HEALTH SERVICES FOR FAMILIES OF DEVELOPMENTALLY DISABLED PEOPLE

Richard L. Rubin M.D.

Confusion and Conflicts

Discussions of mental health services for families of developmentally disabled people often seem like the group of blind men who met an elephant. Each insisted the whole was like the part he felt. The one feeling the leg said the elephant was like a tree, the one feeling the tail insisted it was like a rope, and so on. Each was correct, but only for himself, not the others. Such conflict and confusion interfere with distinguishing narrow and irrelevant aspects of mental health from modern services useful for many. Should we still see mental health facilities as the old custodial warehouses for handicapped people? Or is the beast like the experts who labeled parent reactions as neurotic, offering psychotherapy when practical programs were needed? Is it the caseworker who advises institutional placement when a child's behavior changes, or the physician who prescribes tranquilizers for aggressiveness without asking your child what may be frightening him? Do all mental health professionals assume behavior problems are the parents' fault? Are all mental health programs like the child

guidance clinic which refuses to see the retarded? Does the beast's medical model prevent a developmental approach? Can mental health treatment and therapy coexist with special education and behavior training? Must we parents still be wary of professionals who exploit our problems? Is psychiatric hospitalization a one way ticket to institutionalization?

I feel that many of the circumstances behind these questions need no longer interfere with appropriate mental health services to families of developmentally disabled people. The best of today's mental health approaches need not continue yesterday's problems. Mental health should not be viewed as a social philosophy or political movement. Mental health practitioners can work with other professionals serving the handicapped if all are willing. The modern mental health field can be seen whole, working beside the other helping professions if we focus on its pragmatic value and functions. These are simply to decrease mental health problems in the handicapped and their families through prevention and treatment. The mental health approaches I will discuss here are selected for mentally retarded children and adolescents who are part of a family system. My emphasis will be on the family as the primary source of human development and what mental health can do to support this.

Modern Definitions and Principles

A widely accepted modern definition describes mental health problems as disorders of thoughts and emotions which have sufficient

severity or duration to cause significant distress or problem behavior. Several principles need stating to use this definition with the retarded and their families. First, mental health disorders are different from the cognitive and adaptive deficits of developmental handicaps. Too often, behavior from mental health problems is erroneously assumed as part of the retardation. Consequently, adequate evaluation is not pursued and treatment opportunities are overlooked.

Secondly, concurrent mental health and mental retardation services are compatible. Mental health problems can be helped by several modalities, including counseling, psychotherapy, consultation, medicines, and specialized programs such as residential treatment. These procedures should be applied only when and as long as needed, and only in addition to the other valuable services required by retarded people and their families. Good mental health treatment should provide for, not exclude, appropriate mental retardation programming. Similarly, mental health therapy and treatment should be available to the retarded in addition to education and training.

Third, the mental health problems of mentally retarded people and their families are often transient and reversible, not a permanent aspect of their retardation or family fate. Emotional and behavior problems in the retarded are often assumed more serious and permanent than they are. The handicap

is allowed to overshadow more realistic indicators of prognosis, such as the degree of brain damage and the quality of early childhood experiences. Potential for treatment and the capacity for mental health improvement are logical aspects of normalization approaches. Mental health professionals, particularly psychotherapists, have a long history dating back to Freud of rejecting retarded people as hopeless subjects. Gunnar Dybwad[1] observed that these statements about the retarded are like earlier judgments about their lack of educability, now clearly a false and tragic assumption.

Family Mental Health Services

The family has slowly become an alternative focus for the care and development of retarded children, as distinguished from residential institutions where parents lost custody and professional centers where parents lost authority. For those who can live at home, success requires practical supportive services for all families and mental health services for some. With an institution oriented focus, the solution to mental health problems in a retarded person living at home was either placement or counseling for the parents to cope better and accept their difficult situation while on a waiting list. A professional centered focus led to repeated evaluations and an odyssey thru medical, mental health, mental retardation, education, and social programs with little direction and much

fragmentation of the family. With a family centered focus, several forms of preventive and therapeutic services are possible for mental health problems.

Preventive Services

Applying my basic definition of mental health services as those which prevent or improve mental health disorders, I must begin by acknowledging the value of many practical services such as medical care, social work, legal advocacy, economic counseling, home management training, parent organizations, and rehabilitation programs. These all help reduce stress and prevent mental health problems in a general way. However, these should be distinguished from the services which prevent mental health disorders in more direct, specific ways.

The first is skillful management of telling parents the mental retardation diagnosis. Parent emotional reactions to having a handicapped child have received voluminous attention. Multiple variations of stages have been described. In the fifties and sixties, much emphasis was placed on the psychodynamics of these reactions. Then parent advocacy efforts began to blame inadequate and harmful services for their strong feelings and allegedly irrational behavior such as doctor shopping. The questions is still open as to how much these emotional reactions are an inevitable part of human psychology and how much they can be influenced by environmental circumstances.

The initial reaction at the time of diagnosis has received much attention. Parents continue to express dissatisfaction about their physicians. Physicians are frustrated with parents or avoid dealing with this unpleasant task. Several approaches have been recommended in the literature, but little consensus exists. Professionals often blame each other when the child and family do not proceed to needed medical, rehabilitation, or education programs.

My wife, a special educator, and I studied this problem by interviewing parents of young handicapped children about their experiences in the initial diagnostic conference.[2] We evaluated various circumstances for their contribution to parent satisfaction or dissatisfaction with the interview. Then we correlated the degree of satisfaction with participation in medical and early childhood education programs. We found that the interview circumstances and the physician's manner significantly influenced the parents' subjective sense of satisfaction with the experience and contributed to positive and negative emotional reactions. Satisfied parents followed the physician's recommendations. Contrary to common belief, we found no difference between the satisfied and dissatisfied parents in lag time until enrollment in a special education program, and concluded that administrative factors usually imposed delays, not the parents' feelings and behavior. Guidelines from this study which parents reported as promoting satisfaction are listed in Appendix 1.

Secondly, I see preventive mental health value in our increasing knowledge about early childhood attachment and individuation, and how these processes are affected by developmental disabilities.[3] This is too large and complex an area to cover here, but I feel that some mental health disorders in the handicapped may result from problems in the family's promoting of attachment and individuation. Pediatric and psychiatric teams are beginning to work in newborn nurseries and high risk clinics. Special educators are applying these concepts in infant programs. I expect that some important benefits will result.

Thirdly, we know very little about how parents can improve the emotional development of handicapped children. We have learned to prevent harm, as through neglect in institutions. But even without blatantly harmful circumstances, the mentally handicapped face significant obstacles to emotional and interpersonal development. Stimulation efforts have emphasized cognitive, language, and physical skills. I suspect that mental health problems in emotional and social areas can be reduced by similar stimulation efforts with families playing a major role.

Fourth, parents can receive preventive and maintenance mental health benefit from services which reduce the psychological distress resulting from the state of having a handicapped child. Roos[4] calls these "existantial anxieties" to distinguish them from psychopathology and mental health disorders. These

existential anxieties are feelings of vulnerability, aloneness, inequity, abandonment, and disillusionment. Important services which relieve this distress are parent discussion groups, more experienced parents counseling those with a newly diagnosed child, and advocacy efforts. Certain mental health techniques are useful for helping the emotional change and growth demanded by these existential challenges, such as gestalt therapy for developing new interpersonal roles and rational emotive therapy for changing ideas and attitudes which are no longer adaptive. The preventive mental health value of these services occurs thru limiting the contribution of the existential anxieties to more serious disorders such as parent depression and family conflicts.

Fifth, I wish to develop the concept of periodic family consultations as a preventive mental health service, provided by professionals with understanding of both mental health and mental retardation. I find there are many events in the course of family life with a developmentally disabled child that should be helped from a combined approach. A common one is difficulty in programming for a child with both organic developmental deficits and mental health problems. Informed diagnostic work is needed to determine appropriate services and interpret the situation to parents and other professionals such as teachers and therapists. Currently, families often feel split among the mental health, mental retardation, and education systems, and action is

often deferred until a crisis occurs. Family consultations which address these combined needs in a consolidated approach and regularly anticipate future problems can prevent the unfortunate consequences of such crises.

A recurring time of need for combined mental health and mental retardation evaluation occurs during common stressful events in families with a handicapped child, such as school entry, plateaus in progress, medical relapses, the changes of puberty, institutional placement concerns, early adult efforts at independence, and parent aging. When changes in the child occur at these times, it is important to distinguish appropriate emotional and behavioral reactions from new mental health disorders. Transient and treatable problems should not be misinterpreted as permanent changes requiring inappropriately severe efforts such as institutionalization.

Real mental health problems can begin at these times. The emotional and social demands of each new stage challenge each person's handicap and personal vulnerability. Periodic family consultation can provide some help in preparing for these events and minimizing adverse mental health effects. I have found many parents eager for a professional who would pay attention to both their mental health and developmental disability concerns, integrate the complex and often contradictory evaluation findings, clarify the complex diagnoses, and discuss practical efforts with understanding and credibility in both fields. In addition,

this family consultation provides an opportunity for attention to siblings and grandparents, two groups often disregarded. They are usually significantly affected themselves by the handicapped child and have strong potential to both help and burden the parents.

Therapeutic Services

The direct treatment of mental health disorders is an underutilized resource for families with a handicapped member at home. The mental health literature of the past twenty years contains several good reviews of counseling and psychotherapy with retarded children, adolescents, and adults.[5] Such efforts are ignored by most mental health practitioners. Many parents and mental retardation professionals regard psychotherapy as mysterious or menacing and avoid any such referral. Even when mental health services are sought, satisfaction is often not found. The result can be the loss of treatment opportunities as maladaptive behavior becomes habitual or problem children are forced into more restrictive care. I do not propose converting all the retarded into psychiatric patients, but rather to add temporary services for the minority who develop significant mental health disorders, consistent with family life and normalization goals.

While professional territoriality continues to be a problem, I find that psychotherapists and mental retardation counselors share more similar ideas in their literature and practice

approaches than is often acknowledged. I think better services would be available if the common ground was emphasized instead of the boundaries. I like to describe these similar mental health approaches under the inclusive name of counseling therapy. Do not mistake this for a panacea; we still know too little about treating emotional, cognitive, and behavioral disorders in the retarded. Realistic limitation of goals is often required, and the more severely retarded and organically impaired usually benefit little from counseling therapy approaches. The challenge remains for families with retarded people at home to create a demand for such services from unresponsive mental health professionals and mental retardation agencies, and for professionals to research the large areas of need.

Direct mental health treatment services for families of retarded people have been controversial. Parents have objected to the labeling of their emotional reactions as neurotic. Recent publications tend to emphasize practical support through information and training rather than mental health counseling or psychotherapy. I feel parents are served poorly by overly narrow approaches. Flexible choice among the several types of family services is needed. I am concerned that in our efforts to normalize the parents' reactions and provide needed practical support, the minority of families who suffer significant mental health problems related to the retarded member are being neglected. Mental health diagnosis and counseling therapy approaches are

needed for these, in addition to the other valuable services such as home management training, social assistance, parent groups, and advocacy efforts.

You are probably familiar with Menolascino's operational approach to assessing family reactions, which distinguishes Novelty Shock, Reality Stress, and Personal Value crises.[6] I have found this system useful for evaluating and clarifying priorities in family needs. More comprehensive mental health services can be provided by our adding a fourth category which I call Family System Reactions (Appendix 2). This concept is based on three basic principles about families. First, each member needs the others for survival and growth. Second, a problem of one member affects all the members. Third, interpersonal events and processes occur in families that are greater than the sum of the individual members. The mental health problems that I call "family system reactions" result from disorder in three basic family functions which are: 1. rules; 2. roles, and 3. effective communications. Problems in family rules occur when they are excessive, deficient, or distorted. Roles may become rigid, diffuse, or distorted. Scapegoating and "eternal" child assignments are common with handicapped children. Distorted communications cause practical or emotional harm, as in double binding, pseudomutuality, and negative expectations.

The procedure for assessing family system problems is a family interview. Serrano has formulated guidelines for such

family evaluations.[7] When observations of the family group and background information are combined, five types of causes for these rule, role, and communication problems can be identified[8]. First, these may be reactions to a child's problem. This has been the traditional focus of work with families of the handicapped. Second, the child and family may react to parent problems. It is under-recognized that handicapped kids, like all others, may show behavior problems for this reason. For example, a child may withdraw or show provocative, self-defeating behavior in response to a parent's depression. Third, the family system can react to a marital problem. I often see children become aggressive or hyperactive in response to a covert parent conflict, but too often the handicapped child is labeled deviant or disturbed. Fourth, the reactions can result from maladaptive beliefs such as family secrets or myths. Many attitudes and ideas about mental retardation can interfere in this way. Fifth, basic family disorganization and lack of differentiation causes severe problems. These families usually have chronic deficiencies in living skills, often associated with poverty, abuse, and social instability.

My basic procedure for intervention in family system reactions begins with clarification of background circumstances, precipitating factors, and the family function problems. The next step is to develop a working relationship within the family

system, particularly recognizing sources of power for change. Then various techniques can be applied to change the dysfunction processes, such as interpretation, reframing, or directive prescription. Next, opportunities for the family to develop more functional rules, roles, and communications are facilitated throuth techniques such as working through, addition of outside resources, problem solving, modeling, and role playing. While many families can resolve these problems with termination of counseling therapy, ongoing maintenance may be needed for the disorganized family.

As in much counseling and psychotherapy work, qualities of the practitioner are often more important than the techniques used. Both mental health skill and understanding of mental retardation issues are needed to establish credibility with parents regarding their problems and the realities of living with a handicapped child. This credibility is necessary for the accurate empathy which makes for an effective working relationship and better outcome. In addition, the professional's acceptance of retarded children leads to including them more in the counseling therapy process with added benefit. I have found that the emotional sensitivity of retarded people and their ability to benefit from the sessions is often greater than their cognitive handicap would suggest.

Appendix 1

Guidelines for the Initial Diagnostic Conference with Parents of Developmentally Disabled Children.

Annette Lisa Rubin M.S., M.Ed.
Richard L. Rubin M.D.

1. Communicate an attitude of concern for the child and family.

2. Communicate awareness of the child's value to the parents as a loved person, no matter how severe the handicap.

3. Plan the place and time for the conference. Include both parents. Conduct it in an unhurried manner.

4. Try to delay giving the diagnosis until after the parents have seen the baby.

5. Appear well informed about developmental disabilities and share extensive information with the parents.

6. Give some impression about future possibilities and prognosis, but avoid definite and extreme predictions.

7. Make specific recommendations about what the parents can do, including medical care, practical assistance, social services, habilitiation and education programs, etc. as needed.

8. Schedule additional meetings with the parents for ongoing follow-up.

Appendix 2

Family Evaluation and Counseling Therapy Guidelines

I Reality Crisis

II Novelty Shock

III Personal Value Crisis

IV Family System Reactions

Observed and felt distress results from problems to basic family functions:

1. Rules- excessive, deficient, distorted.

2. Roles- rigid, diffuse, distorted (scapetoat, eternal child, enmeshment, triangulation, etc.)

3. Communications- practical or affective harm (double binding, pseudomutuality, negative expectations, etc.)

Causes:

1. Reaction to child problem

2. Reaction to parent problem

3. Reaction to marital problem

4. Result of maladaptive beliefs (secrets, myths)

5. Result of basic family disorganization and differentiation.

Intervention techniques:

1. Clarify precipitating factors and function problems.

2. Develop a working relationship within the family system, particularly recognizing the power sources.

3. Influence the process maintaining the function problems (interpretation, reframing, modeling, etc.)

4. Facilitate opportunities for the family to develop more functional rules, roles, communications (homework, working through, outside resources, etc.)

5. Ongoing maintenance for the disorganized family.

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CHAPTER 8

THE NEEDS OF DEVELOPMENTALLY DISABLED PERSONS AND THEIR FAMILIES

(Summary of Group Discussion Results)

Patty Smith and John McGee, Ph.D.

Parents of developmentally disabled children express a need for a broad range of services. They state that the needs of the families of disabled children are only partially and sporadically met across the state. Ironically, if families are to remain intact and if developmentally disabled children are to have the same opportunity as all other children to grow and develop in family and community settings, there must be rapid movement away from the current agency-centered service system to a family based service system.

The Family Conference outlined the basic needs of families with developmentally disabled children. In outlining these needs, we gain a clearer picture of the needs of families with disabled children in Nebraska. The following is a list of the needs cited by 120 parents and professionals relative to the necessary services for these families:

Rank Order	Needs	Frequency
1.	Resource Coordination	8
2.	Public Education and Information	6
3.	Respite Services	4
4.	Early Identification and Intervention	4
5.	Day Programs, Including 12-month Education Opportunity	4
6.	Monitoring of Services	3
7.	Financial Assistance	3
8.	Parent training	3
9.	Recreation	3
10.	Transportation	3
11.	Development and Maintenance of Parent Organizations	2
12.	Parent Counseling	2
13.	Legal Services	2
14.	In-Home Services	2
15.	Residential Alternatives	1
16.	The Guarantee of Basic Human Needs Being Filled	1
17.	Adequate and Appropriate Treatment	1
18.	Services in Rural Areas	1
19.	Extension Services	1

It is clear from this rank order of needs that there is a broad spectrum of services required by families with developmentally disabled children. Many of the needs which were cited related to three broad areas:

1. Parent-centered Services: It became obvious in the Family Conference that many parents were perplexed by the added challenge of having a developmentally disabled family member. This perplexity was expressed in the need for parent-centered types of services such as parent training and parent counseling. It was fel that if there were a network of strong community based parent associations across the state, many parents of developmentally disabled children would receive the basic types of support which these families require.

2. In-home Services: Conference participants also focused on a range of services which would assist the family in maintaining the child at home for as long as possible, such as respite services, financial assistance, in-home support services, recreation programs, etc.

3. Out-of-home services: Participants also cited a number of services outside of the family setting such as trnsportation, day programs, and community based residential alternatives. It was strongly felt that such out-of-home services should be based on the needs of the individual child, especially those with severe disabilities. Most parents and professionals felt a major need for on-going (12-month) out-of-home day programs.

4. Systemic needs: Conference participants felt a strong need for

   a) the coordination of resources on a statewide and local level; and

   b) public education and information.

   Parents and professionals felt that there was little coordination of the existing resources in the state. The typical parent is confused when confronted with the "System". There appears to be little coordination of all types of services and programs. Each parent felt that he or she was virtually on his own in relation to acquiring adequate and appropriate services. Conference participants also felt a basic lack of education and information when confronted with professionals dealing with developmentally disabled persons. This lack of knowledge ranged from insensitivity to ignorance on the part of physicians, nurses, law enforcement officials, social workers, etc. There was also a strong emphasis placed on the need for general public education, ranging from elementary education through university training. Included in these systemic issues was the problem of the lack of legal services when a family is confronted with an unresponsive service system.

5. Extension Services: Conference participants felt that needs of families were even greater in the rural areas. It was suggested that the major resources in the state, concentrated in the Omaha-Lincoln area, have a responsibility to extend themselves into the rural areas of Nebraska such as MCRI, Barkley Center, etc.

Resources for the Families of Developmentally Disabled Children

For every lack of services cited by conference participants, another participant could name a resource available in the state. Thus, the issue is not one of no resources available to meet the needs cited by parents and professionals, but rather the sporadic and temporary nature of most family support services. Conference participants listed out the primary resources available in the state for families of disabled children. These resources were:

1.	Advocacy groups and services (for example, Nebraska Advocacy Services, United Cerebral Palsy Association, Spina Bifida Association, Nebraska Association for Retarded Citizens, Nebraska Society for Autistic Children)	12
2.	Health Agencies (Visiting Nurse Association, Public Health Nurses, University of Nebraska Medical Center, Meyer Children's Rehabilitation Institute, Boystown Institute, Red Cross, etc.)	14
3.	Limited Respite Services	5
4.	Direction Services (Child Find)	4
5.	Parent Counseling Services (Mental health centers and child guidance centers)	4
6.	Pilot Parent Programs (Parent Education and Training Services)	3
7.	Early Intervention Services	3
8.	Limited Recreation Services (Lincoln-Omaha YMCA	3
9.	Special Education and Education Service Units (Including the Meyer Children's Rehabilitation Institute and Barkley Center	4
10.	Limited In-home services (Lincoln	2
11.	Limited County Extention Services	2
12.	Transportation Services (Omaha-Moby)	2
13.	Easter Seal Society	2
14.	Legislation	2
15.	Adaptive Equipment	1
16.	Building accessibility	1
17.	The Eastern Nebraska Community Office of Retardation	1
18.	Vocational Rehabilitation	1

19.	Financial Assistance	1
20.	March of Dimes	1
21.	Nebraska Services for Children (Adoption)	1
22.	The Beatrice State Developmental Center	1

It is obvious from this listing that there exists an array of services supportive of families with disabled children across the state. However, it must be noted that nearly all of these resources are either very limited in scope, not readily accessible, or dependent for their survival upon local initiatives. The above resources fall into the following five categories:

1. Consumer Advocacy: There is a number of consumer advocacy organizations across the State of Nebraska, but clustered in the Omaha and Lincoln areas. A perpetual problem of consumer advocacy organizations is the lack of financial support necessary to provide services supportive of families in an on-going guaranteed basis.

2. Generic agencies: A number of generic health related agencies were cited as having a potential for providing support to families. However, such agencies as the Visiting Nurse Association have been infrequently used by agencies attempting to create support to families.

3. Family Services: Services such as respite and in-home care were invariably described as "limited". This clearly indicates that there are a few services spread across the state supportive of families, but they typically serve a narrow population and have little on-going support.

4. Information and Referral: Direction Services, Child-Find, etc. were cited as responsible for the early identification of children accessing of services and the early provision of child-related services.

5. Day Services: Special education and educational service units were cited as generally providing adequate and appropriate day services for developmentally disabled children. These services have their foundations in state and federal law. Thus, they seem to be, at the present time, our greatest strength in relation to child-centered services offering some support to the families of disabled children. Such services also include community based mental retardation programs such as the Eastern Nebraska Community Office of Retardation. However, these community based programs are continuously plagued by waiting lists. Thus, in the post school-age grouping, there is no guarantee for on-going day and residential alternatives.

A comparison of the needs which were cited to the available resources demonstrates a fragmented family support service system across the state. There are some services. They are typically marked by inadequate funding. There is generally a tendency to have these services in the metropolitan areas of Omaha and Lincoln. The further one goes into rural Nebraska, the less opportunity there is to find and utilize family support services.

Families with developmentally disabled children are confronted with a fragmented service system. If the family is fortunate, it resides in an area where a particular

service is available. If it is unfortunate, it is confronted with a confusing service delivery system. These families appear to be left on their own.

The general tone of the Family Conference focused on the need for a broad array of services, supportive of families across Nebraska. It was felt that many special and generic agencies could be better utilized in the development of this array of services. It was clear that the technology was available for these services. We know how to provide training for parents. We know how to develop in-home support services. We know how to develop respite care services. What is lacking is a state-wide service delivery system focusing on the needs of these families. By defining what the system looks like, it should be possible to mobilize, in a large majority of instances, current generic and special agencies to develop this sort of system.

CHAPTER 9

LEGISLATIVE ISSUES

John J. McGee, Ph.D.

In the Family Conference's legislative panel, there were three legislative representatives:

1. Senator Jerome Warner, Chairman of the State Appropriations Committee;
2. Senator Don Wesley, Member of the State Health and Welfare Committee;
3. Mr. Dale Siefkes, Research Legislative Analyst for the Education Committee.

In the last decade the State of Nebraska has passed over 60 laws directly affecting handicapped children and adults in Nebraska. Senator Warner was asked to review this historical trend. Senator Wesley was asked to review his proposed legislation entitled, "The Developmental Disabilities Family Assistance Act". Mr. Siefkes was asked to review the impact of LB 889 (the 0-5 school law).

Senator Warner outlined the state Unicameral's historical support of adequate and appropriate programs for the state's disabled children and adults. He reviewed the last decade's substantial reduction in the number of institutionalized mentally retarded persons and described the system of community based mental retardation services which have brought many formally institutionalized mentally retarded persons back to their home community. Senator Warner also described the political realities of the 1980's. The issue of budgetary "lids" will necessitate both community based programs and programs supportive of families to justify themselves on both a programmatic and cost level.

Mr. Siefkes described the current impact of the State's legislation pertaining to handicapped children. He pointed out that because all handicapped children have a right to an adequate and appropriate education from birth, that families now have a viable alternative to institutionalization, or removal of their child from their home to receive services. He also cautioned, like Senator Warner, that the current budgetary mood of the State and Nation will necessitate stronger and stronger justification for all programs and services. But he also felt that the legislative framework for services to handicapped children and adolescents was now well established in the state of Nebraska.

Senator Wesley reviewed his proposed legislation pertaining to the support of families with disabled children. This legislation was modeled on legislation already introduced in five other states. The rationale for the legislation is that children grow and develop best in families and, therefore, those families should be encouraged to maintain their disabled children at home. He also described the cost benefit rationale of such services. In other words, Senator Wesley pointed out that by spending a relatively small amount of money to support the child at home, the savings in future costs (that is, institutionalization or community based programs) would be significant.

CHAPTER 10

THE STATE OF NEBRASKA'S ROLE IN SUPPORTING THE FAMILY

John J. McGee, Ph.D.

As part of the Family Conference, four state administrators were asked to review their agency's historical, current, and future roles relative to supporting, rather than supplanting, the families of developmentally disabled children. The various agencies and their spokespersons were:

1. Dr. W. Ralph Michner, Director, State Department of Public Institutions;
2. Dr. Henry Smith, Director, State Health Department;
3. Mr. John Clark, Assistant Director - Special Education, State Department of Education;
4. Mr. William Hogue, Chief of Medical Services, State Department of Public Welfare.

The mobilization of resources, financial or other, depends upon a concerted effort among these various state agencies. It is clear that the State of Nebraska has historically had a number of programs supportive of families of disabled children. From the consumer perspective, however, these various programs are often contradictory and difficult to access. Beyond this difficulty, many parents of disabled children feel strongly that there are more disincentives to maintaining the handicapped child within the family than there are incentives to placing the child outside of the family setting, for example, into large instittuions. Thus, the state administrators were asked to review the incentives and disincentives towards family support services in Nebraska.

Department of Public Institutions

The state administrators' panel pointed out that the state of Nebraska, for the last decade has developed a national model of community based mental retardation programs and services. This has resulted in returning hundreds of mentally retarded persons back to their home community, as well as preventing hundreds of persons from being placed outside the family. This, in itself, has been a major breakthrough towards supporting, rather than supplanting, the families of mental retarded children. Several disincentives, however, were pointed out in this discussion. Such as the fact that many families are still forced to institutionalize their mentally retarded child because there are long waiting lists of other families in the community for services in community based mental retardation programs. There appears to be no ceiling on the number of persons who can be institutionalized at any given point in time, on the other hand, there is a finite number of "spaces" available in community based programs due to budgetary constraints.

Dr. Michner was very supportive of the state moving in the direction of supporting families with disabled children in order to prevent the need for both institutionalization and admission even into community based mental retardation programs. He recognized the fact that such a trend will necessitate legislation supportive of the concept, as well as a more coordinated utilization of current services already available to various state agencies.

State Department of Health

Dr. Smith stated that the State Health Department is a regulatory agency rather than a provider of services. He felt that his agency could play an important role, both now and in the future, in relation to monitoring the quality of care of both institutional and community based services for

developmentally disabled persons. This has been, and will continue to be, at least an indirect support to families. By monitoring the quality of care and regulating such quality, the State Health Department is able to ensure these families that their sons and daughters will be served by programs with a maximum quality of care for as long as they are in such programs.

He also pointed out that the State Developmental Disabilities Council and Office has historically been very supportive of the concept of family services. This conference was financed through the State Developmental Disabilities Council and focused on families with disabled children. He felt that in future years the State Developmental Disabilities Council would play an even larger role in focusing on the gaps currently in existence in this state relative to family support services. Through the identification of these gaps, the State Developmental Disabilities Council could provide innovative approaches to meeting the needs of these families.

Department of Public Welfare

Mr. Don Hogue reviewed the Department of Public Welfare's current program which relates to supporting handicapped people and their families. Such programs and services include the various income maintenance programs (S.S.I.) and the various medical service programs such as the Crippled Children's Service. He stated that these Department of Public Welfare programs tended to provide family support services dependent upon the various eligibility criteria inherent in each of their respective programs. He pointed out that in the future more concentration could be given to better coordinate D.P.W.'s services supportive of families and handicapped individuals and assisting both in accessing these monies.

Department of Education

Mr. John Clark reviewed the current legislation which affects all school age children in the state of Nebraska. He pointed out that in the state of Nebraska all handicapped children now have a right to a free public education from the date that they are identified as being handicapped. From birth through five this right is used at the discretion of the families. From five years of age through 21, all handicapped children must be provided a free and appropriate education in the least restrictive setting. In the pre-school legislation, he went on to say, there are provisions within the Department of Education regulations to permit in-home educational services. He felt that this was a major step towards supporting families of newborn handicapped children and in the long-run, preventing unnecessary institutionalization. Mr. Clark concluded that, because the laws state that handicapped children have a right to a free public education from birth (or the point of diagnosis), in the upcoming years handicapped children in the State of Nebraska will increasingly be in such services and that their families will be supported in maintaining their handicapped children at home.

Conclusion

The state administrators' panel demonstrates that there are many programs and services available for the families of handicapped children in the state of Nebraska. It also becomes clear, however, (as reported by parents who attended the conference) that oftentimes these services are difficult to access; the least restrictive services often have funding limitations; there is little coordination among the various state agencies to facilitate access towards these programs and services; and, if families are to be maximally supported, there must be major social policy changes at both the legislative and the administrative level to coordinate the flow of these services.

CHAPTER 11

CONSTITUTIONAL ISSUES FOR FAMILIES IN NEBRASKA

Bruce Mason, J.D., and Annette Mason, J.D.

Focusing in on families, and particularly those families with developmentally disabled children, we must first analyze policies, and how these policies are established through legislation. The legislature, specifically through the appropriation of funds for families, raises the question of what "value" the legislative branch puts on maintaining families which have developmentally disabled members. To date, the emphasis has been on a substitute for the family, either temporarily or extended in nature. The most prevalent has been a permanent substitute in the form of institutional care in the form of "voluntary placement" in institutions which, if closely scrutinized, are really coerced placements because of a lack of any viable alternative to aid or assist families with developmentally disabled members. One example of this was a mother who had multiple sclerosis and was unable to care for her daughter. Because of this mot her's handicapping condition, and because she had sole responsibility for her daughter, she had to go through juvenile proceedings so that the court could assume custody and guardianship rights to assure that the child would be placed in another home. This is an example of a situation where it's either all or nothing. That is, because of this mother's handicapping position, she wanted to be with her daughter and maintain that kind of mother-daughter relationship in her own home via some supportive services. But the system did not allow for this. Instead, the daughter was placed outside the home. This was the only way that parental care could be assured for the girl.

The major question that must be posed, then, is whether or not the "Voluntary Placements" brought about by the nature of the present federal

and state legislation and the commitment funding mechanism are really class based intrusions into family life and liberty protected by the due process clause and first amendment rights recognize by the Supreme Court in a series of opinions. An example of this would be the Sundheimer vs. Kolb case. A New York court recently held that the State Family Care Program was unconstitutional. The program paid parents to care for their children if they had been institutionalized for at least two years. This program denied family payments to parents if no institutionalization had preceeded home care. In effect, the court found that the statute was penalizing families who opted for home care. In other words, the consequence of this type of statute was to coerce families into choosing institutional care in lieu of exercising any liberty interests or first amendment rights of the family unit.

At the present time, legislation with regard to families with developmentally disabled individuals can be found in certain laws such as TITLE XVI, TITLE XX, Supple Security Income, Medicaid, HUD Subsidies, Section 504 of the Rehabilitation Act, and Public Law 94-142. However, as a matter of public policy, we grossly undersubsidize family care while at the same time lavishly supporting care outside the family setting. The reasons for this are obvious:

1. The perpetuation of existing institutions;
2. The belief that paying parents to care for their own children is morally wrong;
3. Accountability of direct payment;
4. Competition with big business, that is, delivery of health services;
5. The perception that families of handicapped persons are deficient units unable to function adequately as a family

unit within the norms of society.

The system, as it presently exists, ensures failure of the family unit. Instead of maintaining equilibrium of the family, the system creates a self-fulfilling prophecy, that is, that families with developmentally disabled members cannot exist as a family unit, and therefore justifying continual state and federal intervention. The concept of normalization and mainstreaming really should be recognized within the parameters of the First Amendment Right - Freedom of Association (Pappochristo vs. Dade County). The freedom of association should be extended as well to families with developmentally disabled members who should be allowed, through the process of normalization and mainstreaming to integrate themselves into society. This first amendment protection derives from the recognized best interests of the family as primary care taker, supporter, and developer of children. In looking at the goals for the 80's, we must emphasize support to families and not the supplanting of families. We must focus on the role of legislation, the role of the courts, the role of social planning in which we analyze the state vs. the parent, the parent vs. the child, and how to best maintain the family unit while still deriving constitutionally minimal standards of care. The emphasis must be on family freedom and not in lieu of the family experience.

APPENDIX

FAMILY RESOURCE SYSTEMS: THE NEBRASKA MODEL

"SUPPORT NOT SUPPLANT THE FAMILY"

THURSDAY, January 24, and FRIDAY, January 25, 1980

CONTINUING EDUCATION CENTER
University of Nebraska Medical Center
42nd and Dewey Avenue
Omaha, Nebraska 68105

and

RAMADA INN CENTRAL
7007 Grover Street
I-80 Exit at 72nd Street

THURSDAY, January 24

8:00-9:00 AM REGISTRATION - Coffee and Rolls

9:00-12:30 PM MORNING ACTIVITIES - Amphitheater, Continuing Education Center

Overview of Conference — *Paul H. Pearson, M.D.*, Director, Meyer Children's Rehabilitation Institute

Keynote Address

Introduction — *Neal A. Vanselow, M.D.*, Chancellor, University of Nebraska Medical Center

Address — *Mrs. Charles Thone*, First Lady of Nebraska

Future Directions for Families — *Patty Smith*, Parent Activity Consultant, MCRI

International Prospectives in Family Services

Introduction — *Joan Wentz*, Chairperson, Nebraska Governor's Council on Developmental Disabilities

Address — *Robert Perske*, Author, Lecturer, Family Advocate - Darien, Connecticut

12:30 PM LUNCHEON BUFFET - Lobby

1:30-4:30 DISPLAY OF 13 LOCAL PROGRAMS THAT SERVE FAMILIES OF HANDICAPPED INDIVIDUALS
Resource Room - Lecture Room 2

1:30-2:20 CONCURRENT WORKSHOPS

A. Utah Cooperative Extension Agent and Parent Training Projects
Exceptional Child Center, Utah State University, Logan Utah

Glen Latham, Ph.D., Director, Extension Agent Project
Cy Leise, Workshop Moderator
Amphitheater

B. Parent Respite Care Co-op Program
Kalamazoo Family and Children's Services, Kalamazoo, Michigan

Beverly Gallagher, Coordinator, Parent Co-op Program
Sally Lindsay, Co-op Member
Barbara Jessing, Workshop Moderator
Lecture Room #1

C. Nebraska Toybrary and Parent Resource Project
State Department of Education, Lincoln, Nebraska

Linda Esterling, Workshop Moderator
Telephone Conference Room

D. Colorado Respite Service Coalition, Archdiocese of Denver
Denver, Colorado

Cary Carron, Director, Ministry of the Handicapped
James Quinlan, Ph.D., Workshop Moderator
Lecture Room A

2:20-2:30 Break and Refreshments

2:30-3:20 CONCURRENT WORKSHOPS (repeat session)

3:30-4:20 CONCURRENT WORKSHOPS (repeat session)

7:00-9:00 PM LEGISLATIVE ISSUES: Nebraska's Incentives and Disincentives for Family Support

Senator Thomas Kennedy
Senator Donald Wesely
Senator Jerome Warner
Dale Siefkes, Research Analyst for the Education Committee (representing Senator Gerald Koch, Chairman of the Education Committee)
Dave Powell
Dee Everitt Moderators

*** PLEASE NOTE CHANGE IN LOCATION ***

RAMADA INN CENTRAL
7007 Grover Street
I-80 Exit at 72nd Street

FRIDAY, January 25

8:30-9:00 AM Coffee and Rolls

9:00-10:30 EVERYTHING YOU ALWAYS WANTED TO ASK A PSYCHIATRIST

Introduction — *Frank Menolascino, M.D.*, Associate Director Nebraska Psychiatric Institute

Address — *Richard Rubin, M.D.*, Child and Family Psychiatrist Miami, Florida

10:30-12:00 RESOURCES FOR FAMILIES: Issues and Disincentives

SMALL GROUP SESSIONS *

Group Assignments — *Jack Stark, Ph.D.*, Director, Family Rehabilitation Dept., MCRI
Bertine Loop, Coordinator, Family Advocacy Project

12:00-12:45 LUNCHEON BUFFET - Lobby

12:45-1:30 CONSTITUTIONAL ISSUES FOR FAMILIES IN NEBRASKA

Introduction — *John McGee, Ph.D.*

Address — *Bruce Mason, J.D.*
Annette Mason, J.D. Legal Advocates, Omaha

Amphitheater

1:30-2:30 REGULATION ISSUES IN NEBRASKA: The Role of State Agencies

Henry Smith, M.D., Director, State Department of Health
Don Hogg, Chief of Medical Services State Welfare Department
Ralph Michner, Director, State Department of Public Institutions
John Clark, Asst. Director, Special Education, State Department of Education
Edward Skarnulis, Moderator

Amphitheater

2:30-2:45 Break and Refreshments

2:45-3:55 STRATEGY WORKSHOPS; Recommendations for Action and Implementation

SMALL GROUP SESSIONS *

Group Assignments — *Jack Stark, Ph.D.*
Bertine Loop

Amphitheater

* Participation in the small group sessions is extremely important for the success of this conference. Please return to the same group for the second session.

MAJOR CONFERENCE SPONSORS

Nebraska Governor's Planning Council on Developmental Disabilities
Meyer Children's Rehabilitation Institute

CO-SPONSORS

Easter Seal Society of Nebraska
Epilepsy Council of Omaha
Greater Omaha Association for Retarded Citizens
Nebraska Association for Retarded Citizens
Nebraska Psychiatric Institute
Nebraska Society for Autistic Citizens
Spina Bifida Association of Nebraska
United Cerebral Palsy of Nebraska

WORKSHOP MODERATORS
GROUP LEADERS AND FACILITATORS

Mary Clark, Family Advocate

Patrick Collins, Social Worker, MCRI

Cheri Dean, Family Advocate

Linda Esterling, Early Childhood Regional Coordinator, MCRI

Dee Everitt, Chairperson, NebARC Legislative Action Committee

Phil Gray, Family Advocate

Rose Hoover, Chairperson, Mayor's Commission on the Handicapped

Barbara Jessing, Advisor II, Eastern Nebraska Community Office on Retardation (ENCOR)

Diane Kratochvil, Coordinator, Nebraska Deaf-Blind Program, MCRI

Cy Leise, Direction Services Project Manager, MCRI

Fran Porter, Family Advocate

Dave Powell, Nebraska Association for Retarded Citizens (NebARC)

James Quinlan, Ph.D., Psychologist, Family Rehabilitation Department, MCRI

Edward Skarnulis, Clinical Manager and Instructor, Dept. of Family Practice University of Nebraska Medical Center

Sheri Soucha, Family Advocate

RESOURCE ROOM

DISPLAY OF 13 LOCAL PROGRAMS
SERVING FAMILIES OF HANDICAPPED INDIVIDUALS

Program	Representative
Easter Seal Society of Nebraska	David Evans
Eastern Nebraska Community Office on Retardation (ENCOR)	Paul Fileman
Epilepsy Council of Omaha	Carol Zickefoose
Greater Omaha Youth Association for Retarded Citizens (GOYARC)	Beverly DeMay
Meyer Children's Rehabilitation Institute (MCRI)	Diane Kratochvil Susan Svanberg Gwen Weber
National Society for Autistic Children	Linda Flowers Ginny Friend
Nebraska Association for Retarded Citizens	Pat Rowan
Pilot Parents - Greater Omaha Association for Retarded Children (GOARC)	Fran Porter Mary Clark
Project II - GOARC	Nancy Loomis
Social Security Administration	Phillip Gray
Spina Bifida Association of Nebraska	Sheri Soucha
United Cerebral Palsy of Nebraska	Camille Wolesensky
Visiting Nurses Association	Jane Sherratt